

Autism-in-context

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An investigation of schooling of children with a
diagnosis of autism in urban India

Shruti Taneja Johansson



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Abstract

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Informed by the significance given to context in the postcolonial critique of disability in the South, the overall aim of this thesis is to develop a contextual understanding of the schooling of children diagnosed as being on the autism spectrum in mainstream schools in urban India. This is particularly valid at a time where there is an increased focus on bringing children with disabilities into the mainstream classroom. The school, socio-familial, cultural and institutional contexts are foregrounded in the study. Using an ethnographic mode of enquiry, stakeholders' perceptions and practices are explored within an interpretive framework. The data consists of observations in classrooms, interviews with stakeholders and government policy documents.

The thesis is comprised of four articles and a mantle text. The first article examines how inclusive education is conceptualised in government policies and in practice. The second article, describes school staff's awareness of autism and stakeholders' perspectives on children with autism. In article three, factors influencing teachers' practices and responses towards children with autism are investigated. The fourth article explores parents' views on, and experiences of, schooling for their child with autism. Each of the articles provides a nuanced picture of the complexities of the phenomenon in context. The results from the articles are discussed using the metaphor of space, where autism is conceptualized as a space within which the medical, political, social and educational play out.

Apart from offering implications for policy making and practice, this study's main contribution is to the theoretical debates on schooling of children with disabilities. Despite developments in policy, growth in scholarship as well as media, the collective findings from this study show that negotiating access to a school still remains a concern. Even more significantly who is responsible for the learning of children with disabilities continues to be a contested area.

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PART TWO: THE ARTICLES

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ARTICLE IV

Teachers’ responses to children with disabilities in mainstream schools in urban India: An autism lens

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Writing this part of the thesis means that it is finally the end, or maybe as the more enlightened ones keep telling me, it is just the beginning. How would I know; when life has revolved around the same topic for over six years, one can rarely see beyond. However, as the mist slowly rises, what I can see are all those who have in their different ways contributed to the completion of this thesis and also to where I stand today.

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Abbreviations

DfID	Department for International Development
DPEP	District Primary Education Programme
EFA	Education For All
GOI	Government of India
ICF	International Classification of Functioning
MHA	Ministry of Home Affairs
MHRD	Ministry of Human Resource Development
MSJE	Ministry of Social Justice and Empowerment
MSPI	Ministry of Statistics and Programme Implementation
NCERT	National Council of Educational Research and Training
NCTE	National Council for Teacher Education
NGO	Non-Governmental Organisation
NUEPA	National University of Educational Planning and Administration
PROBE	Public Report on Basic Education
PWD Act	The Persons with Disabilities (Equal opportunities, Protection of Rights and Full Participation) Act
RCI	Rehabilitation Council of India
RTE Act	Right To Education Act
SSA	Sarva Shiksha Abhiyan
UEE	Universalization of Elementary Education
UNICEF	United Nations Children's Fund
UNESCO	United Nations Educational, Scientific and Cultural Organization
WHO	World Health Organization

Part One

THE STUDY

1. Setting the agenda

It is Friday and the last lesson before lunch. The subject is history and the teacher introduces the new topic of ancient civilizations which is going to be their focus during the next few weeks. She then asks the students to share what they know about the topic and why it is important to study it. A girl starts describing the pyramids. Suddenly and for no obvious reason, Andreas jumps up from his chair and starts running around the classroom making loud sounds. His classmates look up and observe Andreas for a second or two after which they return to the discussion, seemingly ignoring the boy's sudden uproar.

This is a scene from a 5th grade Swedish classroom. The teacher turns to me and states “Andreas has autism, they do that” and struggles to carry on with the lesson. A similar scenario is played out in a 5th grade Indian classroom, where Andreas is replaced by Arjun. Arjun's classmates verbally demonstrate their dissatisfaction over his behaviour. The teacher remarks to me “Arjun is naughty, he does not listen. His parents give him too much freedom”. Subsequently she reprimands the child and instructs him to stay in the class during recess. In essence comparable behaviour of two children across countries but understood by teachers in contrasting ways, leading to distinctly different responses. One could claim that the Swedish teacher is aware of autism and responds in a more appropriate manner than the teacher in India. However appealing this argument is, it is problematic. The Swedish teacher by solely accepting the behaviour as part of the package of autism does not try to understand why the child might be doing so. In contrast, the Indian teacher with no knowledge of autism draws on her existing frame of reference of the ‘naughty child’. Based on my personal experience, the teachers’ expression in both countries highlights the complexities that arise by either linking all the child does to autism, or not making any link to autism, where neither teacher possibly respond to the needs of the child.

This lays the genesis of my interest in the exploration of the role of context in how the disability autism is understood and responded to. My experience working with children on the autism spectrum in three different countries led to my initial curiosity in this area of research. I was intrigued by how children with a diagnosis of autism in India, Sweden and England, might

have similar characteristics but various contextual factors seemed to shape how it was manifested, understood and the educational and societal response to it.

Aim and research questions

Context has increasingly become part of the discourse around inclusive education, particularly when investigating it across different countries (Artiles, Kozleski, & Waitoller, 2011; Mitchell, 2005). However, it is within current debates in postcolonial disability theory that context has been raised as not only important but the most fundamental to the understanding of the phenomenon of disability in the South. Making this argument Grech (2011, p. 90) states, “Engaging with the nuances of context is necessary, at the very least, because disabled people experience all or most of the aspects of economy, society and politics as other people do ..., and it is within this context that meaning of disability is negotiated and experiences are lived.”

Postcolonial researchers critique the continued neglect of context in the contemporary disability discourse. Meekosha (2011) shows how the dominant social model developed in the North is not able to capture the complexities of disability as it plays out in different countries of the South. Not only is the adequacy of this context-insensitive social model lens been raised but also its misleading nature. Grech (2011) argues that the application of the social model in the South has led to the focus in research, policy and practice on the barriers in the setting and what is not happening in the South. As a result, there has been little attention given to understanding the actual concerns and opportunities for people with disabilities (Singal & Muthukrishna, 2014).

This thesis on schooling of children with disabilities is informed by these arguments raised by postcolonial researchers on disability in the South¹. Drawing on their critique, the overall aim of this study is to develop a contextual understanding of the schooling of children diagnosed as being on the autism spectrum in mainstream schools in urban India. Under the assumption that context influences people’s lived realities, experiences and local meanings, the main research question addressed in this thesis is: What are stakeholders’

¹ While this study is informed by the critique raised on disability in the South by postcolonial researchers, it does not share their theoretical point of departure which is rooted in the cultural legacies of domination through years of imperialism, colonialism and globalization. Neither does the study take on their orientation towards a critique of Western science and its adverse effect on the disabled.

perceptions and practices towards educating children with autism in mainstream schools in urban India?

While the postcolonial critique provides an overarching argument for why and in what way context is important, it provides little support in terms of how to investigate context in this study. The Oxford dictionary (Stevenson, 2010) defines context as, “the circumstances that form the setting for an event and in terms of which it can be fully understood”. However for a study on schooling of children with autism, there could be numerous aspects of the context that could possibly be incorporated. Context is after all a complex multi-dimensional construct. One of the few who have developed a model for investigating context in the field of special education are Artiles and Dyson (2005). They have used a theoretically derived understanding of context to develop a comparative model for investigating inclusive education. However, keeping in mind the lack of research on the schooling of children with autism in India, I chose to adopt a pragmatic and contextually grounded approach to develop a systematic way to understand context in this study. This was also in keeping with the postcolonial critique framing this study and was done by drawing on the existing knowledge and understanding from within the Indian setting. More specifically, information gathered during a pre-exploration² of the field was complemented with insights from literature on autism and disability in India, to identify the dimensions of context to be investigated in this study.

The four dimensions of context and the reasons for foregrounding them are briefly discussed below. Listing the contexts in this manner gives an impression that each of them is a self-contained definite environment. However, these different contexts are not only highly interrelated but also each context is in itself multilayered. The main purpose of elucidating them here is to provide an account of the explicit frame from within which I approached this exploratory study.

1. *School contexts* – The focus of this study is on *schooling* of children with autism, making the school context essential to engage with. The pre-

² Prior to starting this study I conducted a pre-exploration of the field to get a sense of what was happening in the Indian context. I gathered basic information through a questionnaire e-mailed to professionals in India, such as clinical psychologist, psychologist, psychiatrists and special educators on how a child receives a diagnosis of autism and what happens after that (for more details see p. 55).

exploration of the field highlighted four groups of stakeholders who were generally associated with the child with autism in a mainstream school: principals, special educators, counsellors and class teachers. Understanding this context thus entails an exploration at two levels, the wider school context, as well as the specific classroom context.

2. *Socio-familial contexts* – Parents have been central to the disability developments in India (e.g., PARIVAAR, 2015), this is even more so the case for autism. The autism movement in India has been parent driven from its inception and it is a result of parental advocacy that the disability is now recognized (Action for Autism, 2014; Brezis et al., 2015). This role of parents in autism developments in India have not gone unnoticed in academic literature, particularly in the fields of anthropology, sociology and psychology (e.g., Feinstein, 2010; Grinker, 2008; Vaidya, 2008). This literature highlights the limited awareness and services available for autism in India and how parents are playing an important role in every sphere of their child's life. This is supported by the information obtained during the pre-exploration of the field, where parents were identified as the central participants prior to and post diagnosis, making the social and familial context integral for this study.
3. *Cultural contexts* – 'The significance of culture in shaping parents' and medical professionals' responses to autism in India has been highlighted in a number of studies using a medical lens, particularly focusing on diagnosis and treatment (Daley, 2004; Grinker, 2008). For instance, Daley (2004) found that culturally shaped norms about child development determine what is perceived as a problem or 'abnormal' by parents, influencing the help they seek before and after the diagnosis. Culture has also been frequently shown to have a pervading impact on how disability is understood in India (Edwardraj, Mumtaj, Prasad, Kuruvilla, & Jacob, 2010; Rao, 2006; Vaidya, 2008). Thus making it essential to explore the cultural context within which the phenomenon of schooling of children with autism takes place.
4. *Institutional context* – Previous research shows how the term inclusive education has gained popularity and become part of the official rhetoric within different levels of the education system in India (Singal, 2004).

In policy and practice, inclusive education has been perceived as an issue which relates solely to the provision of education of children with disabilities (Hodkinson & Devarakonda, 2009; Singal, 2006a, 2006b). Alongside this consensus, studies have frequently highlighted the ambiguity, confusion and discrepancies surrounding the concept of inclusive education in government policies and among practitioners (Hodkinson & Devarakonda, 2009; Julka, 2005; Singal, 2006b, 2008). Nonetheless, the institutional context is not static and the findings from the aforementioned studies are reflective of a certain time and space. The policy context in India is rapidly changing and evolving. In the last decade policy developments have taken place within the general mainstream educational system, as well as specifically for children with disabilities. Thus making it of interest for this study to not only understand the institutional context through the national policy discourse, but also investigate the specific policies made at school level.

In line with the aforementioned dimensions of context, the specific sub-research questions revolve around:

- How are schools in urban India responding to the education of children with autism?
- How do teachers understand and respond to the needs of the child with autism in their class?
- What are the parents' views and experiences with mainstream school for their child with autism?
- How is inclusive education conceptualized within these schools in the existing socio-political context?

These questions have been addressed in the four research articles attached to this thesis and the summaries of the articles are presented in chapter 5.

While my personal experience led to the interest in elucidating the context of disability education through the perspective of autism, I also find it to be a powerful lens to explicate the intricacies and influences of context when it comes to the schooling of children with disabilities in India. There is a clear hierarchy around different types of disabilities in policy, among researchers and the public debate in India (Mehrotra, 2011; MSJE, 1996). The focus has dominantly been on individuals with physical and sensory disabilities. When a

specific group gets overwhelming attention, it increases the likelihood that other disabilities get neglected. In particular the peculiarities associated with a hidden disability like autism and the associated subtleties of learning are unlikely to come to the forefront. Unlike physical and sensory disabilities, there are no direct and concrete helping aids for autism, which is likely to bring attention to classroom practice (cf. Singal, 2006b). Furthermore, research and frequent media accounts show a general reluctance among schools to include children with autism (Narayan, Chakravarti, David, & Kanniappan, 2005). These factors together make autism an exciting and powerful lens to explore the phenomenon of schooling of children with disabilities in context.

Outline of the thesis

The following chapter 2 highlights the problem area by providing a background on the education of children with disabilities in India and a review of the existing research literature on the topic. Chapter 3 presents the theoretical perspectives that have influenced the formation of this study and elaborates on the autism lens used to explore the issue in question. Chapter 4 attends to the methodology underlying the research. The epistemological and ontological position, methods of data collection, presentation of the informants, details of the research process and a description of how the analysis was conducted. The chapter ends with a discussion of ethical reflections. Chapter 5 comprises the summary of the four accompanying articles. Chapter 6 provides an analytical summary of the findings, the contributions of this study and concludes with some critical reflections.

2. Setting the scenario

India with a population of 1.17 billion has 194 million school aged children between the ages of 6 to 14 years³. This has resulted in India having the second largest education system in the world (Little, 2010), which is as diverse as a country with 22 official languages, 9 religions and large income disparities. Since independence in 1947, India has expressed a constitutional commitment to Universalization of Elementary Education (UEE) which has been reinforced in the subsequent policies (Singal, 2010). A recent culmination of this engagement is the 86th amendment of the constitution in 2002, in which education has been established as a fundamental right for children between the ages of six to fourteen.

There has been significant progress in the last 60 years, where the literate population has increased from 18.33% in 1951 to 74.04% in 2011⁴ (MHA, 2011). Remarkable improvement is also noticeable in school enrolment rates which has gone from 83.5% in 2000 to 98.2% in 2008 (United Nations, 2012). A similar positive trend is visible from data on completion of primary education, 63.8% in 1991 to 85.7% in 2006 (UNICEF, 2011). Nevertheless, India is unlikely to meet the Millennium Development Goals to achieve UEE by year 2015. Recent figures estimate 8 million children still having no access to school (UNICEF, 2011). It is important to note that this figure is a low estimate of out of school children as it is based on enrollment not on attendance or on those who drop out before completing primary school.

In pursuing the goal of elementary education for all, numerous programmes and schemes have attempted to address the education of the groups marginalised among others by dimensions of gender, caste, poverty, location and religion (Singal & Jeffery, 2011). For example, those belonging to the scheduled castes and scheduled tribes⁵ have long received benefits of positive discrimination in education, among others through reservation of seats, spe-

³ Estimated population in 2005 (MHRD, 2008)

⁴ Literacy rates from 1951 census relate to the population aged 5 years and above. Whereas literacy rates for 2011 relate to population aged 7 years and above.

⁵ Scheduled castes and scheduled tribes are the official designation given to various groups of historically disadvantaged people in India.

cial hostels and ‘ashram’ schools, as well as extra support through coaching and grants for books (Planning Commission, 2002). However, in comparison children with disabilities have only recently received considerable attention (Miles & Singal, 2010). Developments at the international level, particularly international mandates and policy proclamations have resulted in changes at the national level (Singal, 2009), with an increasing number of legislations and policies specifically addressing disability. The most significant of these is the Persons with Disabilities (PWD) Act, 1995 (MSJE, 1996). With the passing of this Act, people with disabilities in India became visible in legislation for the first time. The PWD Act also brought attention to the educational rights of a child with disability. Article 26 mandates the Central and State governments to “Ensure that every child with a disability has access to free education in an appropriate environment till he attains the age of eighteen years” and “...endeavor to promote the integration of students with disabilities in the normal schools” (p. 14).

Not only did the PWD Act bring to the forefront a group of people long marginalized, disability also entered the public discourse through increased media focus. An initial impetus was a mandate under the PWD Act to raise awareness on causes of disability and preventive measures (Kalyanpur, 2008). However, now the topic of disability is regularly visible in newspapers. For instance, a search in a leading English language newspaper, *The Hindu*⁶ for articles on disability published in the online version of the newspaper during 2011, led to over 2000 articles. Disability has also permeated popular Hindi primetime talk shows like *Satyamev Jayate*, which devoted a whole episode to disability, titled “Persons with disability. We can fly.”⁷ The programme discussed issues across the life span, among others on rights of the disabled and gave significant emphasis to education of children with disabilities. Additionally, mainstream movies about people with disabilities, like *Black*, *Tare Zameen Par*⁸, *Iqbal* and *My name is Khan*, have reached wide audiences, raising awareness about various disabilities (Boray, 2011).

Further impetus to raising disability issues into the mainstream is credited to the disability movement in India which has continued to become more or-

⁶ <http://www.thehindu.com/>

⁷ <http://www.satyamevjayate.in/issue06/>

⁸ The movie *Tare Zameen Par* portrays a child with dyslexia, who was thought to be lazy, a troublemaker and faring poorly in academics until a patient and compassionate art teacher discovered the real problem behind his struggles in school.

ganised since the late 90s. According to Mehrotra (2011) the PWD Act was the common core that unified diverse disability activists who drew on the common rights based approach to assert their individual goals. The disability movement gained further momentum under a national campaign called Disability 2000 which led to the formation of a National Disability Network. This brought together disability rights organisations and advocacy groups around the country to share ideas, raise awareness and collaborate in decision making process on cross-disability rights issues⁹ (Hosamane, 2007).

Moreover, many of the disability related organisations work across the board from advocacy, raising awareness, empowering parents, provision of service, to collaborate with mainstream schools towards the goal of including children with disabilities (Das & Kattumuri, 2011). As majority of these organisations are based in urban India they frequently reach out to the middle-class through journals, websites and magazines (Mehrotra, 2011). However, how this changing environment with an increased media impetus and organised disability movement is impacting schools and other stakeholders in urban India is yet to be understood.

As disability gained attention, there was also an increased focus on education for this group. While the education of children with disabilities has featured since 1968 onwards in the National Policy of Education (MHRD, 1986) and the associated Program of Action (MHRD, 1992), it was associated for the first time with the UEE policy through the District Primary Education Programme (DPEP). Despite wide coverage the DPEP programme at its peak was restricted to 219 districts in only 15 funded states (Chanana, 2004). Nonetheless it was only in 2002 that education of children with disabilities was addressed for the first time across the country in the UEE policy through the Sarva Shiksha Abhiyan (SSA) programme. The SSA is India's primary program for achieving UEE and lays particular emphasis on special needs¹⁰. It states, "The key thrust of the SSA will be providing inclusive education to all children with special needs in general schools" (MHRD, 2011, p. 46). The emphasis on *inclusive education* when it comes to children with disabilities is a common feature in government policies and programmes (Singal, 2006b).

⁹ In each of the 32 states and union territories, a partner was identified, who would work on various disability rights issues affecting the nation (Hosamane, 2007).

¹⁰ Indian documents often mention children with special needs. It is not defined and is synonymous with children with disabilities.

While it is now acknowledged that UEE in India can only be achieved by taking into account schooling of children with disabilities, they continue to be isolated from the realm of mainstream education. For instance, governance of education for children with disabilities is split across Ministries. While the responsibility for children with disabilities in the mainstream is with the Department of Education in the Ministry of Human Resource and Development, those for children with disabilities in special schools comes under the Ministry of Social Justice and Empowerment. Similarly, Singal (2006b) based on an analysis of inclusive education in government documents, raised concerns on how issues surrounding education of children with disabilities are perceived as separate from mainstream education. This tendency is also visible in education research, where extensive discussions on UEE and quality of education do not usually incorporate children with disabilities. For instance, a recent book “*Who goes to school in India? Exploring exclusion in Indian Education*”, takes up a comprehensive range of issues on access and participation in elementary education for various marginalized groups but devotes little attention to disability (see Govinda, 2011).

Over the period of this research there have been significant developments in the educational landscape in India. The most important has been the passing of the Right to Education Act (RTE) by the Indian parliament in 2009 (MHRD, 2009b), which stipulates free and compulsory education for all children in the 6-14 age group. The Act clarifies that ‘compulsory education’ means a particular governments obligation to provide free elementary education and ensure compulsory admission, attendance and completion of elementary education to every child, including those who have dropped out or face hurdles in admission due to migration, caste, disability among others. Disabilities have been placed under the wide category ‘disadvantaged groups’, and includes all disabilities, as listed in the Person with Disabilities Act, as well as the National Trust Act¹¹ (see p. 43 for details). Moreover, another landmark clause of this act is that private unaided schools are now mandated to reserve a minimum of 25% of the seats at the entry level class for children belonging to economically weaker sections of society and disadvantaged groups. The latter includes in its realm children with disabilities. However there are numerous ambiguities surrounding this clause and its actual

¹¹ The Act was amended a month after to include children with disabilities listed under the National Trust Act (MSJE, 1999) (like cerebral palsy, autism, mental retardation and multiple disabilities), after pressure from disability rights groups.

implementation in practice (Srivastava & Noronha, 2014). It will be interesting to see how this maps out in the coming years, specifically if and how it impacts inclusion of children with disabilities into the mainstream. While the RTE Act is a landmark development, important to highlight here is that during the time this study was conducted the RTE Act was not part of peoples realities, thus what I observed and heard was not related to this.

Research on schooling and education of children with disability in India

The bulk of literature on the schooling and education of children with disabilities in India comprises of articles and books providing descriptions, overgeneralisation from personal experiences and/or commentaries on children with a particular disability, special education, inclusive education and special schools (see e.g., Alur & Bach, 2010; Byrd, 2010; Shernavaz, Evonn, & Radhike, 2002). However there is a small, growing but dispersed body of empirical research that has investigated this field¹². A dominant strain of research is large scale statistical studies which attempt to estimate the number of school aged children with disability in India and/or the number currently enrolled in schools. There are however wide variations between the results from numerous studies and the accuracy and reliability of the figures are questionable (Singal, 2009). Nevertheless, there is a general consensus across these studies that despite government efforts, educational participation of children with disabilities is low. A report from the World Bank revealed that children with disabilities rarely progress beyond primary school and are five times more likely to be out of school than those from Scheduled Castes and Schedule Tribes (O'Keefe, 2009). These figures though interesting tell us little about why this is case.

An area that has featured frequently in discussions and reports but received little attention in research is special schools. The few existing studies have used an inventory scale, questionnaire or secondary data to investigate diverse areas such as professional teamwork within special schools (Rao & Suryaprakasam, 2004), regional variations between special schools in areas like human resources, number of enrolled students and service facilities (Rao &

¹² There are possibly other independent studies and projects undertaken by various research institutions but these are less frequently reported.

Reddy, 2004) and success rate of special education based on dropout rates from special schools (Kalita & Sarmah, 2012). While there are an increasing numbers of special schools (Singal, 2008) there is little knowledge about what happens there. Nonetheless, in comparison to mainstream schools, special schools play a minor role in the education of children with disabilities in India. Data suggests that only 5.7% of children with disabilities attending school are enrolled in special schools (O'Keefe, 2009).

Another line of research gaining increasing popularity has focussed on surveys to investigate school staff and pre-service teachers' attitudes and concerns towards disability, education of children with disability in the mainstream and inclusive education (Bhatnagar & Das, 2013; Parasuram, 2006; Shah, Das, Desai, & Tiwari, 2013; Sharma, 2009; Sharma, Moore, & Sonawane, 2009). These studies together paint a bleak picture and highlight unfavourable attitudes among teachers in general. Nonetheless, this unidimensional focus on attitudes in these studies provides only one part of the picture, it is well acknowledged that the relationship between attitudes and practice is more complex (Chaiklin, 2011). What happens in the classroom is shaped by many other contextual factors which are more multifaceted and nuanced.

There is a small but growing recognition of adopting a qualitative approach to explore the complexities of the field. Since education of children with disabilities in India gained momentum under the purview of inclusive education, recent research has used the lens of inclusive education to investigate this area. A particular characteristic of this body of research is its association with the notion of 'inclusive schools'. Inclusive schools are schools that are perceived as making an effort to admit and include children with disabilities. These schools often have a mandate towards inclusive education and provide some extra support, usually through special educators, special section and/or alternative curriculum (Das & Kattumuri, 2011; Hodkinson & Devarakonda, 2009; Singal, 2006a, 2008). Drawing their sample from inclusive schools, these studies have explored among others, meanings and perceptions of inclusive education among practitioners (Hodkinson & Devarakonda, 2009; Singal, 2004), school culture for inclusion (Sandill & Singh, 2005; Singal, 2008), leadership issues and experiences of children with disabilities in inclusive schools (Das & Kattumuri, 2011).

While these studies provide rich accounts on children with disabilities in schools, they have neglected pedagogical practices within the classroom. There is little research which looks at what teachers are actually doing during

lessons¹³. Moreover, I argue that exploring the issue only through the lens of inclusive schools is limiting. Even though current data shows low participation of children with disability in education, one cannot overlook the fact that the majority of children with disability are attending mainstream schools. A World Bank report based on National Sample Survey 2002 data concluded that 94.3 % of children with disabilities attending a school in the age group 5-14 are in a mainstream school (O'Keefe, 2009). While there are increasing numbers of schools with children with disabilities enrolled, there is yet little research on understanding what happens in these settings, whether these are 'inclusive' or not.

This review of the research on schooling and education of children with disabilities in India shows a predominance of studies embracing a quantitative approach, often focusing on narrow dimensions. Among the few qualitative studies in the field, teaching practices from within the classroom have been neglected. Moreover, majority of these studies have been restricted to schools that claim to have an inclusive mandate. These gaps in the literature is partially what I sought to address in this study which aims to develop a contextual understanding on children with disabilities in mainstream schools in India, with particular focus on children with a diagnosis of autism.

Clarifying North-South terminology

In this thesis the terminology North-South are used to differentiate between two groups of countries, where India is part of the South. The terms were first formulated by the West German Chancellor, William Brandt in 1980 in the Brandt commission report, 'North-South: a programme for survival'. The intention of this divide was not related to geographical northern southern divisions but to highlight a socio-economic divide. It stressed the stark economic inequalities between the two blocs in living standards, availability of resources, and the high dependency of the South on the North. What is interesting is that many of the countries that are part of the South have been dominated in the past by colonial powers that are all part of the North resulting in the continuing of unequal relationships and dependency. While it is well acknowledged that this binary categorization is a simplification of the existing heterogeneity residing within a country and between countries in the same bloc,

¹³ Though, Singal (2004) does briefly touch on it in her doctoral thesis, it is only a complement to the primary interview data.

Singal and Muthukrishna (2014, p. 1) discuss how over the years North-South has “become shorthand for the complex set of inequalities and dependencies between countries divided... by... fundamental economic inequality”. There is an assumed simplicity of this divide, as it implies that world can be divided into two camps. Nonetheless, I chose to use North–South in this study as it moves away from the implicit hierarchy embedded in terms like developed–developing, east-west, first world–third world, to actually capture the complexities of the relationship between these different groups of countries.

3. Theoretical perspectives

This chapter accounts for the various perspectives that have informed the formation and shape of this study. It starts by mapping out the landscape of the wider debates on disability and the influence of these on how learning needs of children are being understood and responded to within the field of education. Following this the emerging postcolonial critique on disability in the South is elaborated on to provide the rationale for the focus in this study on ‘developing a contextual understanding’. The final section delves on the autism lens adopted in this study, the contradictions surrounding the diagnosis and the reason for focusing on the disability autism within the Indian context.

Perspectives informing education of children with disabilities

Three contemporary perspectives on disability are presented in this section: the individual, the social and the biopsychosocial. These are then shown to link to current or emerging parallel perspectives on how educational needs are understood and responded to within the field of education. While each of these perspectives have had specific dominance at a certain time and reflect a historical development of ideas and practice, they all continue to coexist.

The individual perspectives

For large part of the 20th century disability has been understood and defined through a dominant medical lens. Within this the causation of disability is seen as intrinsic to the individual and a consequence of a real existing biological deviation in functional limitations or psychological losses (Oliver, 1990). As the impairment is seen as the sole reason for the disability, the focus within the individual perspective is on identifying, treating, compensating and/or eliminating the defect within the person, by providing individual medical inputs from specialists and professionals. This is frequently referred to as the medical model.

A parallel response towards educational difficulties are visible within the field of education (Clough, 2000). An individual perspective has as Nilholm

(2007) describes traditionally dominated the field of special education. It has among others been referred to as functionalist (Skrtic, 1991), psycho-medical (Clark, Dyson, & Millward, 1998b; Skidmore, 1996), compensatory (Haug, 1998), individualistic (Ainscow, 1998) and categorical (Emanuelsson, Persson, & Rosenqvist, 2001). The commonality shared across the previous named is that it ascribes the problem to the individual, where certain individual characteristics and abilities are perceived as the reasons for the educational difficulty. Adopting a positivist view of the world this perspective assumes that the difference between learners is 'real' and that school difficulties are a result of deficit in the individual. This knowledge on difficulties faced by children in school has its foundations within the disciplines of medicine and educational psychology. With such an individual focus, the emphasis is on identifying, categorizing, diagnosing and compensating for the educational difficulties within the child through special inputs. Thus within this perspective, special education is seen as a rational response to the educational difficulties, which provides a scientifically proven suitable intervention to the child compensating them for these deficiencies.

The social perspectives

The dominance of the individual perspective to educational difficulties was brought to question in the early 1980s and was in many ways a reflection of the wider debates then operational within the disability field. The 1970s saw the rise of the people with disabilities in Britain and North America, the growth of disability movement (Anspach, 1979), and the coming to the fore of the social model of disability (Oliver, 1990). Distancing itself from the medical understanding of disability, the social model claimed that people with disabilities are an oppressed social group and perceived society as the main factor disabling people, not the person's impairment. These developments resulted in attention being directed in disability debates towards identifying structural barriers, negative attitudes and intentional/unintentional exclusion by society.

These developments in the field of disability, in particular the rise of social model of disability have significantly influenced the field of special education (Slee, 2011). The 1980s onwards saw an increasing critique of the psycho-medical explanation of educational difficulties in terms of learner characteristics. The commonality shared across these diverse studies which adopted an

eclectic mix of approaches and analysis, was their conceptualization of educational difficulties as a 'social product' and arising out of social processes (Clark, et al., 1998b). Forerunners of this were the sociologists of education, significant here is Tomlinson's (1982) critique of special educational needs in Britain which is seen as a milestone in the development of social analysis in the field. Directed at the level of wider structural and socio-economic processes, Tomlinson located educational difficulties in the broader context of institutional reproduction of inequality and social disadvantage, rather than a case of individual deficit. Moreover, Tomlinson questioned the place of special education within the educational system, where identification of children with educational difficulties was argued as serving the vested interests of certain professional groups, in particular those within the medical and psychological field, to maintain their own status and power.

Educational difficulties have also been explained by drawing on an organizational paradigm (Skidmore, 1996). Within this framework it is argued that problem is not in individual child, rather a failure at the system level. According to this systems limitation perspective, educational difficulties are those that the educational system or schools are unable to meet due to shortcoming in the way they are organized. Skrtic (1991) critiquing how special education has been seen as rational response to educational difficulties, claims how it was actually put in place to manage the inadequacies of the educational system. Moreover, since schools are seen as unable to respond to the diversity of the students, focus within this approach has been directed towards identifying factors that would facilitate this response by schools and also how to approach bringing about this change in schools (Clark, Dyson, Millward, & Skidmore, 2004). Others have explained educational difficulties to arise through discourse where concepts and categories of need are constructed by schools (Andreasson & Asplund Carlsson, 2009; Hjärne, 2004).

This conceptualization of educational difficulties as social processes taking place at the structural, institutional, school and classroom level has resulted in moving focus from the deficiencies or impairment in children, to a focus on identifying and removing barriers to learning and participation (Booth & Ainscow, 2002, 2011). These barriers are seen as external to the child and embedded in the larger system and the specific setting, in particular at the micro level of the classroom, the middle level school and the macro policy level (Norwich, 2013). These include among others attitudes, physical

environment, the curriculum, school organization, school cultures and policies and teaching approaches.

The biopsychosocial perspective

In recent times it has been acknowledged that there has to be a more holistic understanding of disability, than the extreme binaries of the medical and social perspectives. Forerunners of this critic have been former advocates of the social model within the field disability studies. Shakespeare and Watson (2002) argue that disability has to be understood as an interaction of biological, psychological, cultural and socio-political factors, and emphasize the need to re-conceptualize the social model to include the experience of impairment and move away from the medical-social dichotomy. They claim that different impairments have implications not only at social and structural level but also at individual and psychological level.

These debates among others have led to attempts to redefine how disability should be understood, by drawing on a more nuanced biopsychosocial perspective on disability. This has been operationalized through the World Health Organization's International Classification of Functioning (ICF) (WHO, 2001), which integrates the medical and social perspectives into an interactive, multi-level and multi-dimensional model. In this disability is viewed in terms of interaction of bodily functions, tasks and activities that person can/cannot execute and the persons participation in the current environment. These interrelated dimensions are seen as being influenced by both, health conditions of the individual, as well as contextual factors. These contextual factors are further divided into personal and environmental factors. The environmental factors are described as "the physical, social and educational environment in which people live and conduct their lives. These are either barriers to or facilitators of the persons functioning" (WHO, 2013, p. 5). The fact that ICF acknowledges that disability is not culture free and that the complexity of disability can only be understood within a context, is a significant development.

This multipurpose classification system is designed to be applicable not only across different countries and cultures, but also various disciplines and sectors. Moreover it is not adult driven but has life span coverage, where a specific adaptation of the ICF has been develop for children and youth (WHO, 2007). However unlike the well rooted social and medical perspectives

the thinking around the ICF is still ongoing, with people struggling with how to operationalize this hugely contextual and multidimensional way of seeing disability. While there are numerous concerns still associated with this framework, Shakespeare (2006) does acknowledge it as an important step forward in defining and researching disability and Imrie (2004) raises how this development is not only of conceptual importance but also practical.

These recent developments around disability are also found to be slowly forming the debates within education, where over the recent years there are voices questioning the usefulness of the dichotomizing between the psycho-medical and social perspectives to understand the learning needs of the child. A dominant voice in this relation is Norwich (2013), who argues that education difficulties are not just simply about structural barriers but also acknowledgment of the individual, and highlights the complexity of this interaction. He has over the recent years called for crossing disciplinary boundaries and a bridging of these two perspectives, particularly highlighting the usefulness of the biopsychosocial model which could aid in inter connections between different levels of analysis. In a recent book he argues, “There is a need for an ICF-type classification of function, activity and participation specifically relevant to curriculum and teaching decisions.” (p. 51). However currently within the education field in the North, the ICF has been particularly promoted and developed in relation to breaking the strong link between certain administrative and diagnostic categories that determine eligibility for special or additional provision (Hollenweger, 2011).

Each of these three perspectives discussed above reflect different conceptualizations of the causation of disability, which is either ascribed to the individual, aspects of a society or a synthesis of the two, in the process they all generate universal explanations for how special needs or disability should be understood and responded to. While the importance of context has been acknowledged by the ICF it is only very recently that context has been raised as the key issue of contention in debates surrounding disability in the South, to which I now turn.

Emerging perspectives on disability in the South

Recently researchers using a postcolonial lens have started questioning the homogenizing of the disability discourse within academics, policy and prac-

tice, in which disability is not only de-historicized but also decontextualized (Ghai, 2002; Grech, 2009; Meekosha, 2011). Raising the importance of acknowledging the diversities of social contexts, they argue how the experience of disability in the South is intimately tied to the structural, cultural, economic and political domination of the North over the South, through imperialism, centuries of colonization and globalization. Moreover, they critique how various neocolonial discourses of disability are justified in countries of the South, in the name of rationality, progress and development. When I started my research these debates were just emerging but now they have become central as my own research has unfolded over time. These postcolonial perspectives have influenced my thinking through this study and been central in making me aware of how disability debates in the Southern context are being constructed through a certain lens. As mentioned in the introduction, I draw on this critique to provide the rationale for the focus in this study on 'developing a contextual understanding'. In the following I discuss some of the key arguments central to the critique, which have influenced the formation of this study.

Grech (2011) elucidates how the North, particularly Western Europe and North America have reigned over how disability should be defined and understood. Through the field of disability studies, theories and methodologies developed with the academia in the North have been transported across the globe (Barker & Murray, 2010). This universalizing of the disability discourse is not restricted only to the academic domain but has permeated policies of the countries of the South. This has taken place through international agreements and development agencies that have adopted uncritically the dominant social model of disability (Grech, 2009) and conceptualization of rights (Meekosha & Soldatic, 2011). Moreover, Ghai (2002) raises how even the disability movement in India has been an active participant in universalizing discourses around disability by adopting the understanding of disability rights as in the North, without questioning the biases inherent in it.

Embedded in this universal discourse of disability is an assumption that the theoretical tools of the decontextualized social model are not only adequate but also relevant to deal with nuances of disability in the specific historical, political, social and economic contexts in the south (Meekosha, 2011). However, recently empirical studies which have focused on a deeper contextualized analysis of disability have started questioning the usefulness of the social model in understanding disability in the South (as exemplified by

Anthony, 2011 in the case of disability education in Ghana). Extending this beyond the inadequacy of the social model, Ghai (2002, p. 96) claims that the universal social model, “ignores the harsh realities of disabled people’s lives in countries such as India, which are caught in social and economic marginalization.”

The social model as ill equipped to capture the complexities of disability as it plays out in different Southern contexts, is central to the postcolonial critique. Grech (2011) stresses how it is within a context that a particular disability is not only given meaning but it is also within the specific socio-cultural, economic and political environment that disability is lived, experienced and possible opportunities and limitations faced. Thus the experience of the disability as Groce (1999) describes is bound to be mediated by other factors, among others gender, religion, social status and socio-economic positioning. While the relational in the experience of disability in the South is now being acknowledged, it often abounds with generalized notions of certain groups of people with disability being more oppressed as a result of facing marginalization at multiple levels, for instance not only having a disability but being a woman, from a low socio-economic background. However, these are now being challenged by increasing ethnographic rich accounts from the South which show the complex ways in which disability interacts with various aspects of the context such as gender, social status, type of disability among others (e.g., Mehrotra, 2006; Mehrotra & Vaidya, 2008; Staples, 2011). For instance, Mehrotra (2006), found that in the state of Haryana, India where there is a scarcity of marriageable women, women with disabilities were found to be in a more advantageous position in relation to poor unemployed men.

The complexity of disability in the South has also been highlighted by questioning the limitations of the impairment-disability divide. This has been critiqued in the North too, where arguments have been raised on how impairment cannot be separated from the social reality of disabled peoples’ lived experiences (Shakespeare & Watson, 2002). However in poverty contexts of the South Grech (2011) argues the impaired body becomes central. He claims that where the main source of revenue is often dependent on physical labor, a functional and a healthy body is an essential requirement. Related to this the medical and social as strong binaries in resource constrained countries in the South have also been questioned. Grech (2011) discusses how disabilities in the South cannot be addressed by focusing only on structural barriers, the medical is as essential to take into consideration. Further, Meekosha and

Soldatic (2011) claim that while both medical and social have to be taken into consideration in the South, it is also essential to understand how they interact with each other in specific contexts. They show how impairments are not always ‘natural’ but often socially constituted in the South, drawing attention to how processes of globalization and capitalism result in production of impairment in the South (Meekosha, 2011).

Moreover, limited by the lens of the social model the disability experience in the South has been simplified as one of disproportionate oppression, leading to a unidirectional focus on societal barriers in discourses of disability in the South. This has resulted in stakeholders as well as the country being usually framed within a deficit perspective with accounts of disproportionate oppression and negative attitudes dominating (Grech, 2011). These then reinforce existing discourses of emancipation and liberalization of people with disabilities in the South. Further, Grech (2011, p. 89) claims this belief is then strengthened by the view of a “homogenized ‘third world’ constructed as backward, underdeveloped and often brutal towards its weaker members”. A consequence of these biased constructions, as Singal and Muthukrishna (2014) argue has resulted in a deficit focus on what is *not* happening within a particular setting and what is *not* working, rather than an understanding of the actual concerns as well as strengths and opportunities within a specific context. This myopic vision thus restricts taking into consideration the numerous positive resources in place within a certain setting, as in the family and community support mechanisms in countries like India (Mehrotra & Vaidya, 2008; Miles, 2002).

Another consequence of this focus on oppression and exclusion is that it leaves little space for harnessing the agentic action by people with disabilities and their families to influence their situation. As Grech (2011, p. 90) argues it denies people with disabilities in the South “the ability/possibility to resist and control/change their circumstances and influence other people’s attitudes and behaviours”. This assumption is however challenged by detailed ethnographic studies of people with disabilities and their families (Mehrotra, 2006; Vaidya, 2008). For instance, Staples (2007) study on men with leprosy in India shows how these individuals used their agency to capitalize and exploit their impairment for their livelihood.

Furthermore, the general lack of Southern voices within the literature in the field of disability studies has been subject to critique (Grech, 2011; Meekosha, 2011). Grech (2009) raises the paradox that while the majority of

people with disabilities live in the South (over 400 million), models and discourses of disability have been formulated on the bases of the minority disabled population in the North, in particular the concerns of white, middle-class educated western disabled academics. A lack of acknowledgement of this Northern hegemony on understanding disability has resulted in what Meekosha (2011) describes as a ‘universalizing and totalizing tendencies of the writing about disability’, which she refers to as ‘a form of scholarly colonialism’, leaving little space for Southern voices.

What in essence is being highlighted by this postcolonial critic, as well as findings from previous named ethnographic studies is that engaging with the nuances of the context, through an exploration of lived realities is essential to understanding disability in the South. As Ghai (2012, p. 279) explains “being disabled in India does have a context and a certain meaning. In our attempts to change the meaning, we must recognize the multiple political, social, economic and cultural realities”. Ingstad and Whyte (2007, p. 3) advice is “to start with where people live and their concerns and resources and the particular political ecology in which they are interacting there”. The ambition being not to develop a grand narrative of disability in the South, which Meekosha (2011) and Grech (2009) carefully warn against, as universal discourses they claim will never be contextually appropriate.

To conclude, the main perspective informing this study is the emerging postcolonial critique of disability in the South. In particular I draw on the emphasis it lays on a more contextual understanding of disability. Based on their arguments, the analytical focus in this study is on trying to understand the complexities of how schooling of children with autism takes shape within the specific Indian setting. This in line with the critique is done by accessing the lived realities, experiences and local meanings of stakeholders who are involved in this process. While I do not tap on children’s own school experiences (see p. 55), I draw on people closely associated to them. This study does not intend to view the schooling of children with autism only from the prevalent models of disability, education and/or autism generated in the North but to actually begin to comprehend how people understand and engage with the phenomenon within an Indian context. Moreover, through this study I not only want to identify the dilemmas, paradoxes and tensions faced by stakeholders but to examine and engage with the same, to try and identify contextual strengths and hurdles.

An autism lens

While in the previous section the focus was on the wider perspectives that have influenced this study, this section discusses the diagnosis of autism, as it is the lens through which schooling of children with disabilities is being explored in this study. People on the autism spectrum experience difficulties in social interaction, social communication and social imagination, which is often referred to as the triad of impairments (Wing, 2007). However the expression and combination of these factors vary widely among those with autism and has led to autism being perceived as a spectrum of difficulties rather than a single condition. Despite this general agreement among advocates of autism, there are numerous controversies surrounding the autism diagnosis.

Some researchers claim autism is a neurological based impairment with a biological aetiology, making it invariant across cultures (Cohen & Volkmar, 1997). The argument for autism as a global phenomenon is strengthened by research that identifies similar symptoms across cultures and even in historical writing (Daley, 2002). It has long been assumed that there is a common cause underlying autism but recently there are others who consider autism to be a complex disorder with a combination of multiple causes (Amaral, 2011). With no agreement on causation, Grinker (2008) discusses the subjectivity of a diagnosis of autism which is given based on an assessment of behaviours and not by administering a medical test. This has led to little agreement even within the same country as to what autism is or how to address it. Among the various debates surrounding the diagnosis are even those that question the validity of the different diagnostic divisions of the autism spectrum¹⁴ (Asperger, PDD-NOS, Autism) (Coleman & Betancur, 2005).

In contrast, another group of researchers question the very existence of the diagnosis. Concerns raised are why the diagnostic category of autism came into being and whose purpose it serves. However, these researchers vary widely in their point of departure. This ranges from those who acknowledge a biogenetic component of autism but are interested in highlighting social factors that led to autism's identification, interpretation and remediation (Nadesan, 2005), to others who argue that the neurological difference

¹⁴ The recently released DSM 5 in 2013 has combined four separate diagnoses from the previous DSM IV. These are autistic disorder, Asperger's disorder, childhood disintegrative disorder, pervasive developmental disorder not otherwise specified, into one diagnosis of Autism spectrum disorder.

representing autism is solely socially constructed (Moloney, 2010). The role of the medical profession (Nadesan, 2005) and cultural institutions such as schools (Molloy & Vasil, 2002) in the construction of autism are often highlighted. Even the cultural universality of autism has also come under critic. Arguments on autism as “an illness of modern civilization” and primarily found in economically advanced countries (Sanua, 1984; p. 163), have frequently been raised.

These controversies surrounding autism have been furthered fueled by the documented increase in the number of children diagnosed with autism in many Northern countries, frequently referred to as an autism epidemic (Eyal, 2010). This is exemplified in the recent figures released by Centers for Disease Control and Prevention (CDC, 2010) which estimates 1 in 68 children being on the autism spectrum in the USA, a figure which has doubled since their last 2002 survey. The explanations for this rise vary across different fractions from arguments on changed diagnostic criteria, greater awareness, better detection and overzealous professionals to an actual increase which needs to be solved and explained by science.

Alongside these disagreements, researchers across disciplines have drawn attention to the role of culture in autism. They usually align to the ‘middle position’ described by Daley (2002), acknowledging the universality of autism, but perceive it is susceptible to cultural influences in expression and course. Daley and Sigman (2002) and Daley (2004) use a psychological lens and Grinker (2008) from a medical anthropological lens, show how social and cultural influences shape autism, from what is perceived as ‘abnormal’ to help seeking behaviour before and after the diagnosis. While a similar approach is adopted by Vaidya (2008) in her study on families of children with autism in New Delhi, she uses a sociological lens to understand how culturally and socially shaped norms influence parents’ perceptions of their child, what they perceive as a problem, how they understand the diagnosis and the help they seek out. Extending this to the field of education Kayama and Haight (2014), show how in a Japanese context, culture and education policy interact and inform the educational practices and support provided for children with autism. However, they take a socio-cultural developmental approach which does not see culture as static but continuously in transition through interactions with others beliefs and expectations. Adopting a related dynamic approach to culture, which though rooted in tradition continues to evolve in interaction with external global influences is Anthony’s (2011) study on autism

in Ghana. She shows how cultural values and belief systems (for example religious and spiritual beliefs) impact how autism is perceived and how this perception impacts the educational support provided.

While I acknowledge that there exist numerous debates and disputes around autism, my focus is not on consistency of diagnosis or validity of the concept across cultures. The fact cannot be overlooked that children with diagnosis of autism are present in India but little is known about their schooling.

Reasons for focusing on autism in India

As mentioned earlier, my personal experience led to my initial interest in using autism as a lens to explore schooling of children with disabilities. However, there are a number of other reasons that make an autism perspective particularly interesting in the Indian setting. This was briefly touched on in the introduction and will be elaborated on further here.

There is a visible hierarchy amongst types of disability in the academic, policy and public discourse in India. Academic research on disability in general has largely centered on those with a motor, hearing or visual impairment (e.g., Singal, Jeffery, Jain, & Sood, 2011; Singh & Ghai, 2009). Even in policy there is an emphasis on providing aids and appliances (Singal, 2006b), thus focusing on the primary needs of the group with physical disabilities. Similarly the disability rights movement frequently uses the symbol of a wheelchair leading attention away from differences within the movement, by drawing attention to physical disabilities (Mehrotra, 2011). This limited focus is also evident in the word for disability in the Hindi language ‘viklang’, which does not encompass all disabilities and is indicative only of physical impairment. This domination of physical disabilities across spheres increases the likelihood of ignoring those with other disabilities. In particular the peculiarities associated with a hidden disability like autism and the accompanying subtleties of learning are unlikely to come to the forefront. In this study by focusing on the disability autism, the intention is to expose issues that possibly fail to surface in a study about disability in general.

While disability is often referred to as a homogeneous group, perspectives on and the needs and experiences of those within are widely diverse (Shakespeare, 2006). Social, political and cultural factors impact understandings of various disabilities within and between countries (Grech, 2011). For

instance, the central disability legislation in India, the Persons with Disabilities Act, 1995 (MSJE, 1996) draws on the rights framework but defines disabilities based on categories of disability, amongst which autism fails to feature. As a result of pressure from advocacy groups, autism has been incorporated in a subsequent legislation, The National Trust Act, 1999 (MSJE, 1999). This Act focuses on guardianship and family support and was set up to respond to parents' worries regarding "What will happen to my child when I am no more" (MSJE, n.d., para. 1). This places autism within a framework of lifelong care, with little attention to educational rights. Thus it can be argued that autism is a disability that has been partially marginalized more than others in India.

In addition, disabilities arising from physical and sensory impairments are in many cases preventable and closely connected to poverty and access to good health conditions (DFID, 2000). For example the elimination of polio in India has reduced the number of physically impaired children between the age group 0 to 9 (Singal, 2009). In comparison there is no 'cure' for autism and it is argued to be equally present across socio-economic groups (Daley, 2002). For discussion on the prevalence of autism, its representation in survey and census data and increasing number of children being diagnosed see Article III (p. 6) and Article II (p. 417).

Despite this increase in autism diagnosis in India, there is hardly any attention given to research on schooling and education of children with autism. A wide literature search on empirical research on autism in India published in academic journals between 1990- 2011 found only two of 52 articles on autism addressed scattered aspects of schooling and education. Narayan, Chakravarti, David, and Kanniappan (2005) identified the settings in which education of children with autism was taking place and the feasibility of replicating these schooling models, whereas Lal and Bali (2007) investigated how visual strategy training influenced the development of communication skills for children with autism. Both studies used a quantitative approach and mainly include children diagnosed with both autism and intellectual disability.

The inattention to research on schooling of children with autism is also reflected in the 37 research studies (including Masters Dissertations) carried out in collaboration with two NGOs working with autism in India from 2005-2013 (Daley, Singhal, & Krishnamurthy, 2013). Despite nine different academic institutions within India and 15 institutions from outside India, education and schooling fails to find representation among the studies. Thus, apart

from anecdotal experiences of parents and professionals there is little known about schooling of children with autism in mainstream schools in India.

4. Methodological considerations and the empirical material

Education and disability research in India

Educational research in India has low status and has contributed little to policy making, implementation and practice (Khaparde, 2002). Policy formulations have instead been driven by a planned research based approach, conducted by commissions set up by the state and central government and through the seven All India educational surveys (1957, 1967, 1979, 1982, 1992, 1999, and 2006) (NCERT, 2014). Another characteristic reflective of educational research in India has been the pervasiveness of the quantitative approach by administration of questionnaires, development of standardized tests and statistical analysis of large bodies of data (Raina, 2001). There is also a domination of psychological processes with little reference to socio-cultural, economic and historical issues. A review of elementary education research in India between 1987-1999 found less than 1% of the identified studies using a qualitative approach (Khaparde, 2002). While this is still reflective of mainstream educational research in India, the last decade has seen a gradual change. There is an increasing visibility of ethnographic qualitative studies to analyze school or classroom processes (Sarangapani, 2003; Sriprakash, 2012). However, B  teille (2011) highlights how little is still known about school as an institution, what goes on within it and its relationship to urban or rural community within which a school is located.

While there is in general a dearth of research studies on schooling of children with disabilities, the Indian government has now recognized the need for research-based information in this area. The Action Plan for Inclusive Education of Children and Youth with Disabilities (MHRD, 2005) calls for research to support and develop inclusive practice and has also led to the setting up of centers for Disability Studies in Indian Universities. Similar to mainstream educational research, within research on disability quantitative studies dominate, through statistical analysis of large bodies of data and investigation of attitudes and beliefs through questionnaires (for discussion see p. 27-28).

While there is an increased acknowledgment of other aspects, such as qualitative studies exploring teachers' perspectives on inclusive education (for e.g., Hodkinson & Devarakonda, 2009) and students with disabilities experiences in an inclusive school (Das & Kattumuri, 2011), the classroom rarely features in the analysis.

Ontological and epistemological assumptions

Scott and Usher (2011, p. 10) describe research as “social practice both embedded and embodied”. How my research is embedded has been discussed in the previous chapters but an important question to ponder on is how the research is embodied. This in essence means the ontological and epistemological assumptions underlying this research study. These are discussed further under this section.

This research is located mainly within an interpretivist tradition, which claims that there is no one reality out there waiting to be ‘discovered’ as assumed by the positivistic approach. It assumes that reality is relational and individually constructed through the meanings and understandings developed socially and experientially, resulting in multiple realities (Lincoln & Guba, 1985). These experiences are perceived through culturally and historically located interpretive frames, comprising the pre-understanding which form the basis from which understanding takes place (Scott & Usher, 2011). Here I also align to Gadamer who claimed understanding is interpretation. Thus the researcher and the informants are interdependent, each with their pre-understanding influences the other and construction of reality is a joint activity (Gadamer in Schwandt, 2000).

The interpretive epistemology is of subjectivism where the world does not exist independently of our knowledge. Knowledge is thus relative and subjective and will vary across time and space. This study is hermeneutic in character with a focus on understanding and interpreting (Palmer, 1972) the “complex world of lived experiences from the point of view of those who live it” (Schwandt, 1998, p. 221). In this approach, human action is perceived as meaningful and thus to understand any social action (e.g., schooling of children with autism) one has to obtain the meanings constituting that action from the actors point of view (Schwandt, 2000, p. 296). ‘Verstehen’ (understanding) as a kind of empathetic or participatory understanding of a social phenomenon has influenced the formulation of this research. Thus the direc-

tion of this study is to listen, understand and interpret the variety of meanings given to the schooling of children with disability and in particular autism by key stakeholders associated with them.

The contextual nature of this knowledge which is seen as culturally derived and historically situated makes it appropriate for this study which aims to develop contextual understanding of schooling of children with autism. Moreover, this choice is linked to “a matter of ontological affinity” (Pozzebon cited in Zhu, 2006, p. 107), where this approach to the study resonates my take on reality, which perceives individuals as social agents who act autonomously and intentionally, interpreting their own behaviour as well as that of others. Thus conducted within an interpretive tradition this study gives voices to people involved in the phenomenon in question and understand their take on the problem, as they are the ones shaping what takes place in practice.

Methodology

Based on the assumption that people’s understanding of the schooling of children with autism and their practices are influenced by the context, I adopted an ethnographic mode of enquiry and relied on qualitative tools to gather contextual in depth insights into the field. The aim was to generate rich context bound information (Creswell, 1994). According to Creswell (2007) ethnography is a description and interpretation of a cultural or social group or system. Culture though multiply defined, commonly refers to the beliefs, values and attitudes that structure the behaviour patterns of a specific group of people (Merriam, 2009). This information on behaviours, values and meanings of an individual or group must then be contextualized within the larger perspectives about the group in society, by relating it the local or wider social structures (Walford, 2008a). This fits well with my aim which is to develop contextual understanding of children with autism in mainstream schools in India, providing an opportunity to access not only what is going on in the school context but also its relation to the wider societal influences.

Hammersley (2006) discusses the contested, variable and ambiguous nature of ethnography which makes it important to explain how it is being used in a particular situation. My alignment to an ethnographic approach specifically related to the way I approached the research field, the manner in which data was gathered and the relations fostered in the field. As a process of research, ethnography involves extensive work in the field, gathering information

through observations, interviews, artifacts and materials and by the researcher being immersed in the population of interest (Hammersley & Atkinson, 2007).

The study departs from a typical ethnographic study where a lengthy period is spent in *a* setting or with *a* particular group of people (Jeffrey & Troman, 2004) and is the reason I refer to the study as an ethnographic mode of enquiry. The decision to include multiple sites and participants versus spending a prolonged period in one or more schools was motivated by the fact that it was developing an understanding of the diversity of school situations for children with autism that was in focus. My goal was to understand the multiple perspectives and variety of ways in which school situation for children with autism takes shape, thus spreading my time across a variety of contexts as well as groups of people. In the five months in the field I occupied different geographical and temporal spaces by engaging with people in various settings and times of the day, where they adopted particular roles and responsibilities, accompanied by different frames of reference. By being involved in varied levels of interaction and participation helped me understand both the wider context of inclusive education and disability, as well as in more particular schooling of children with autism.

Methods of data production

I was interested in an approach that could explore stakeholders' current understandings on schooling of children with autism, as well as the existing practices within mainstream schools. Qualitative methods were the inevitable answer, as they provide an opportunity to access spoken, written and observed behaviour (Mertens, 2010). Miles and Huberman (1994, p. 301) explain qualitative methods as offering a "careful description of the settings, people, and events. Such descriptions also have an analytic, interpretative purpose; to illuminate the constant, influential, determining factors shaping the course of events". Thus by using qualitative methods in this study I could obtain a detailed description of the perceptions and practices towards educating children with autism in mainstream schools, as well as illuminate the possible factors that lead to the way the situation is. The underlying belief is that situations are multifarious and to understand the complexity, they must be portrayed from many dimensions (Bogdan & Biklen, 2003). The research entailed the use of the following methods for data production.

Semi-structured interviews

An integral part of my study was to gain access to participants' experiences, views, beliefs, meanings and values, aspects that are impossible to obtain through observation (Hammersley, 2006). In order to understand the social-familial context, it was important to engage with parents to begin to unravel their educational choices and experiences for their child. Similarly in approaching the school context it was essential to have conversations with schools staff to explore how they understand for instance autism and tap on their experiences with and concerns for the child. Finally, it was only through talking to private specialists that the wider socio-familial and cultural context within which the phenomenon in question was located could be comprehended.

An interview though artificially created, is a situation where the researcher can understand the phenomenon in question from the participants' point of view and for participants an opportunity to voice their understanding and reflect on their practices, beliefs and experiences in relation to education of children with disability in general and autism in particular (Forsey, 2008; Walford, 2008a). Interview as a core method is further strengthened by my paradigmatic affiliation where participants are viewed as constructing consciously their own versions of reality, evaluating their experiences and engaging with the world (Scott & Usher, 2011).

Semi-structured interviews were considered the preferred option to unstructured interviews, as I had a specific agenda for each of the groups of informants, as well as relevant topics and areas to be pursued (Arksey & Knight, 1999). Neither was structured interviews seen as appropriate, as the same questions are to be asked, leaving little room to be able to inquire for clarification. Probing participants (Arksey & Knight, 1999) was central in this study where the focus was on trying to explore their meanings on schooling of children with disabilities.

According to Denzin and Lincoln (2000, p. 107) "semi structured interviews provide the researcher with the opportunity to ask individually tailored questions and do not limit the field of enquiry". This provided the flexibility to explore informants perceptions and experiences but within a given structure, alongside offering the informants a chance to shape the content of the interview (Bogdan & Biklen, 2003). I was also aware that there would be time constraints during many of the interviews and this form of interviewing

provided the flexibility to obtain the necessary information within existing limitations.

An interview guide was designed for each group of informants and included major themes to be covered and listed a few factual and mainly open ended questions on the information that was to be obtained. The interview themes for the various stakeholders are presented in Appendix 5. The interview guide used with private specialists varied according to their profession.

A decision was taken to record the interviews after weighing the pros and cons of recording as discussed by Arksey and Knight (1999). Firstly, the pace at which data was collected sometimes led to four interviews in a day. This was particularly the case with parents, who often preferred to meet on a weekend. Elaborating on the notes taken for all interviews on the same day would not have been possible. Secondly, note taking was considered more distracting than recording, as it resulted in less attention directed by me towards the interviewee. Recording allowed concentrating on what is being said by informants and also reduced the formality of the situation, which took instead the form of a casual conversation. Thirdly, it provided the possibility of listening to sections of the interview at home and asking for clarifications at school the next day. Finally, the exploratory nature of this study made it difficult to judge during the interview what information was relevant for future analysis. The chosen equipment for recording was 3x1.5 inches in size, a discrete digital recorder with an attached mini microphone. Participants' reaction to the recording is discussed later on under the research process (see p. 59).

Observations

The second main method of data production was observation. Observations go beyond meanings and beliefs generated by interviews to study the phenomenon in the context that it takes place naturally (Fangen & Nordli, 2005) and provide a "firsthand involvement in the social world chosen for the study" (Marshall & Rossman, 2006, p. 100). The aim of my study was generating contextual knowledge on the schooling of children with autism where school context was one of the foregrounded dimensions and it was thus essential to carry out observations within classrooms where a child with autism is present. This gave me the possibility to describe what people say and do in context not structured by me (Fangen & Nordli, 2005). It also provided me the opportunity to see what is happening in the classroom and what teachers

do, moving beyond descriptions provided by the various stakeholders. Further, it was a way to complement teacher interviews where I had a chance to see what they did, for example special practices and responses adopted by teachers.

Fangen and Nordli (2005) recommend that if studying a largely unexplored area and having limited time in the field, it is important to define some questions that direct ones attention. Spradley's (1980) nine dimensions of descriptive observation: space, actors, activities, object, acts, events, time, goals and feelings was used as reference to develop an observation guide.

It included five main areas of focus: factual description of the class setting, routine and the students, the teaching process from start to finish, focus on all interactions with the child with autism and the general situation in between lessons. The aim was to maintain a narrative account of classroom proceedings centered on the aforementioned.

Research Diary

Throughout the time spent in the field I kept a research diary (an A4 sized notebook). Partially inspired by Nadin and Cassell (2006) it served five functions. Firstly, an organizational aid where I noted dates, duration and details of every event (telephone conversations, informal talks, interviews, observations etc.). As the research involved contact with numerous people, the diary was a central aid in keeping track of what had been spoken about, with whom and when. Secondly, based on my reflections from the interview, observations and other interactions I identified potential areas to pursue, as well as additions and changes to consider in ensuing observations and interviews. Thirdly, I noted my reflections on each interaction as a social encounter by including my impressions and feelings that arose during and after each telephone conversation, interview and observation. This throws light on my own assumptions, values and beliefs and how they can have impacted my research. Fourthly, analytical reflections as they arose during the time in the field. Finally, maintaining a research diary was particularly useful as I spent many months away from Gothenburg, with little opportunity to reflect, discuss and obtain advice from peers and supervisors. Hertz (1997, p. viii) description of reflective practice fits in well with my use of the diary "an ongoing conversation about the experience while simultaneously living in the moment". Thus the research diary was significant in portraying the chronological development of the

research process and also my thoughts and reflections through the process of data production. An extract from the research diary is presented below.

20th March, interview with parent Nalini (14:35-16:15)

Nalini kept stressing on her child being in a school, not which school but a school. She was just thankful for the school allowing her son to be there and nothing more she could or would ask the school for. But why is the school so important, everything seems to be taught at home?

During data production for this study Hammersley and Atkinson's (2007, p. 3) advice on "collecting whatever data is available to throw light on the issues that are the focus of the research", was also adhered to. In order to understand the wider cultural context within which schooling of children with autism was taking place I attended a few workshops, which also gave me a chance to have conversations with a diverse group of people.

One of the things I wanted to engage with was how inclusive education was being discussed in the wider context outside school. An opportunity arose to attend a day workshop on inclusive education organized by a prominent advocate of inclusive education in the city. The workshop was titled "International perspectives on special education" and incorporated lectures on international policies, quality of inclusive education and quality education of children with disabilities from a European perspective. The main presenters were two professors from a European country and a disability activist from India. Of particular interest were the connections made to the Indian setting by the presenters and organizers, as well as the questions asked by the public. Though there were only a few representatives from schools in Kolkata, the workshop provided an interesting opportunity to see how questions concerning inclusive education, special education and disability were related to Northern understanding and influences.

To tap on the wider cultural context, I also participated in a two day workshop on Asperger syndrome and high functioning autism organized by an Autism NGO in the city. This workshop was attended by parents, school staff (mainly special educators and counsellors but also a few teachers) and private professionals. I had interviewed some of these parents earlier. The workshop covered topics from a general introduction to autism, to more specifically education and schooling of children with autism in mainstream. It was not the actual content of the workshop but the questions raised by the public, in particular representatives from schools that were of interest. As I had the op-

portunity to interview some of the school staff at a later stage in their respective school I explored further experiences and understanding from the workshop.

Aside from the formalized methods discussed above I had the privilege to spend time with the informants in a number of informal settings both in school and other contexts. The social aspect is strongly embedded in the Indian culture, where '*Atithi Devo Bhavah*' (Guest is God) is a guiding principle in the Hindu society and was reflected both by parents and in schools. For instance I was usually invited by teachers to join their circle for tea and lunch and share the food they had brought from home. Participating in the gossip and sharing information about myself played a central role in the rapport building and also lead to interesting discussions and insights particularly relevant to the cultural context of the study.

Documents

To access the institutional context, key national policies were a source of data, namely the, Action Plan for Inclusive Education of Children and Youth with Disabilities (MHRD, 2005), National Policy for Persons with Disabilities (MSJE, 2006), Inclusive Education of the Disabled at Secondary Stage (MHRD, 2009a) and SSA Framework for Implementation 2011, based on the Right of Children to Free and Compulsory Education Act 2009 (MHRD, 2011). The selection of government policies was based on two criteria. These policies were to pertain to inclusive education and/or children with disabilities and had to have been adopted during the last decade. These policies were reflective of the larger social political climate and were used to provide a contextual analysis of the setting. However they also provide an interesting lens to see how debates within the field were evolving.

Setting

The study setting is Kolkata, a metropolitan city located in the eastern state of West Bengal. It is an urban vibrant setting, culturally diverse, and a major educational, business and financial hub. It is third most populous city in India, with the metropolitan area including the suburbs having a population of approximately 14.2 million (MHA, 2011). Capital of India till 1911, Kolkata has a rich history and tradition of education and is home to the oldest university

in South Asia, as well as eight other universities. Kolkata is often referred to as the cultural and educational hub of India.

There are 2621 registered schools in the district of Kolkata offering elementary education, where 2019 are government schools and 602 recognized private schools (NUPEA, 2012). In contrast to most other states the government aided private schools in West Bengal are regarded as government schools and come under government administration (Mooij & Jalal, 2009). Private unaided schools are privately owned and funded by user finance. In Kolkata affiliation to a curriculum board results in recognition and that is only required of private schools with grade 8 and higher. Thus there exist many private unrecognized primary schools that do not figure in the official data. Schools mainly use English or Bengali as the medium of instruction. The majority of the schools are affiliated to one of the two national curriculum boards¹⁵ or the state curriculum board. Recently there has been an increase in schools offering an international curriculum¹⁶, often alongside a national curriculum.

Despite Kolkata being a central hub with world renowned universities, a culture where education plays a central role and a large number of school-going children, the topic of education in general is under researched. Early in the research I tried to contact the local office of National Council of Educational Research and Training (NCERT) in Kolkata, known as the State Council of Educational Research and Training (SCERT). After being unable to establish contact over the phone I visited the office in central Kolkata, which I found to be shut. On trying to find out if the office had moved to another location, I was informed of it not existing anymore by an organisation working in the field of education.

The aforementioned along with a number of other factors led to the decision to select the urban metropolitan city of Kolkata as the setting for this study. In particular, research as well as debate on disability, education and inclusion are usually based in cities like Delhi and Mumbai, with little representation from Kolkata (see e.g. Parasuram, 2006; Sandill & Singh, 2005; Singal, 2008). Further, in a pre-exploration of the field (see p. 55), the informants from city of Kolkata highlighted the lack of schools providing support needed by children with autism and also fewer trained professionals in comparison to

¹⁵ Central Board of Secondary Education (CBSE) or Indian School Certificate Examinations (CISCE)

¹⁶ Cambridge IGCSE (usually offered in higher classes) or the International Baccalaureate

the other metropolitan cities. Finally Kolkata was chosen for practical reasons, familiarity with the city in terms of its geography, languages spoken as well as having myself attended 15 years of my schooling in Kolkata.

Informants

According to Creswell (2003) the choice of the sample is based on its usefulness in answering the questions raised in the study and thus involves purposefully choosing participants or sites that best achieve this aim. Selection of the informants was carried out in stages. The first step was to identify the different groups of people and settings that could throw light on the issue in question and then to actually decide which particular individuals and settings to include. As this is an exploratory study to understand the schooling and education of children with autism in India, it was thought necessary to incorporate the key stakeholders in the process to provide multiple perspectives on a complex phenomenon.

The stakeholders were identified based on a pre-exploration of the field which was conducted to get a sense of what is happening in the Indian context. This was briefly referred to in the introduction and is further elaborated on here. Prior to this study I gathered basic information through a questionnaire on how a child receives a diagnosis of autism and what happens after that. Twelve questions were e-mailed to ten professionals working in the four metropolitan cities. These professionals included clinical psychologist, psychologist, psychiatrists and special educators. Through this questionnaire the main stakeholders identified included children with autism, their parents, school staff (principals, special educators, counsellors and teachers) and private professionals operating independent of school. With the exception of children with autism all the aforementioned are represented in this study.

The decision not to include children with autism as one of the informants in the study was based on ethical issues arising from non-awareness of the diagnosis among children. The pre-exploration study, complemented with discussions with a few professionals in the field highlighted how the diagnosis of autism was usually not disclosed by parents to the child. Similar observations were mentioned in an article published in a journal by a leading Autism organization in India (Basu & Barua, 2009). Later, my own experience in the field verified this where only one parent had shared the autism diagnosis with the child.

The inclusion of stakeholders in the study was practically driven and was based on informants being currently associated with a child with autism attending a mainstream school and aged 6-14 years. The age limits were chosen based on free and compulsory education being a fundamental right in the Indian constitution for children in this age group. Keeping in mind that parents do not always share the child's diagnosis with school, contact was only established with schools which had been informed of the child's autism diagnosis. This practical restriction is reaffirmed by Walford (2008b, p. 17) who states that "the complexities of access may require some compromise with the ideal". This indirectly resulted in schools that were settings in which the situation was working for a child with autism. These schools could possibly be referred to as 'good case examples' in the Indian context. However, the majority of schools participating in the study did not have a mandate towards inclusion and were not intentionally admitting children with disabilities. In most cases, children had received a diagnosis of autism after being admitted to the school.

Research process

As the stakeholders associated with children with autism in mainstream schools are largely a hidden group, there were limited options as to how they could be identified. Snowball sampling was found to be the only ethical and practical way to achieve this (Mertens, 2010). Having previously worked in the field of autism in India, I was in touch with a few private specialists working in Kolkata. Taking that as a starting point I obtained further references from them about other specialists. These specialists included special educators, psychologists and doctors and they all provided some sort of private provision to children with autism. In turn specialists were asked to suggest parents who had a child with autism attending mainstream school, who were then contacted. If parents agreed, I got in touch with the school their child attended. In addition, specialists mentioned certain schools that they knew had children with autism enrolled and were also aware of the child's diagnosis, contact was established with these schools too. Interestingly, the selection process incidentally resulted in only private schools being part of the sample. A similar selection process through recommendations by key people outside the school setting was used by Singal (2008) in her study on inclusive education and Das and Kattumuri (2011) in their study on children with disabilities in mainstream schools. In both cases it led to only identification of private schools.

In addition, opportunistic sampling was used where emerging leads and new insights were pursued to include other sources of information (Patton, 1990). This includes not only opportunities to interviews and conversations through chance meetings but also seeking out other sources to obtain a better understanding. For example, I interviewed a few people who were involved in the drive towards inclusive education in Kolkata, with no direct link to autism.

The final sample comprised of semi-structured interviews in 11 schools with 13 principals¹⁷, 11 class teachers¹⁸, 8 special educators and 3 counsellors¹⁹. Additionally, 18 parents²⁰ and 11 private specialists²¹ were interviewed. Classroom observations and informal talks with teachers were conducted in nine out of the aforementioned schools. Details of informants and schools are provided in Appendix: 2, 3 and 4.

Negotiating access

Since this study involved multiple settings and participants the act of negotiating access took place at different levels. Letters providing basic details of the study were formulated separately for schools, parents and specialists according to the advice of Arksey and Knight (1999). It covered the following areas:

- My background and connection to Kolkata.
- A description of the research.
- Why it is interesting to study and who it will benefit?
- People who will be contributing to the study.
- Their involvement in the study.
- The areas that will be covered during the interview or observation.
- The use of the information provided by them.
- Confidentiality of the participants

¹⁷ Some schools had a junior school/senior school principal, as well as a principal for the entire school.

¹⁸ The class teacher had overall responsibility for the class. She took attendance every morning, provided general information to the class and also took some of the lessons. Throughout the day teachers with subject specific knowledge entered the class to take the different lessons, they are called subject teachers.

¹⁹ Five schools had no special educator. In two of these schools the counsellor was associated with the child with autism. The counsellors have a psychology background.

²⁰ Both mother and father were present in four interviews

²¹ Private specialists offer services to parents and the child with autism and are not linked to the school. 5 special educators, 3 child psychiatrists, 2 psychologists and 1 paediatrician were interviewed.

In the most cases the first contact was on the phone and led to initial access. The letters were presented on meeting and with schools access was further negotiated on the spot.

In a few schools the introductory letter was sent through the parents, after which contact was established with the school. The entry to schools was negotiated with the gatekeepers (Hammersley & Atkinson, 2007) who in this case were principals. Their main concern as Walford (2008b) describes too, was disruption to the busy schedule of the classroom and that of teachers. Further, the benefit to the school was something that came up directly or indirectly in all first meetings, as one head said “I am willing but what do I get in return”. In line with Walford (2008b) I developed a mutual relationship in schools and in some cases observed and provided advice to teachers and special educators on children with special needs. After the head teacher agreed to the school participating in the study, she usually informed the department head, special educator or counsellor, they in turn informed the class teacher. Once permission was granted by the principal I did not have to negotiate access with the teachers, counsellors and special educators. Apart from the head teacher other staff showed little interest in reading the introductory letter.

Prior to referring parents to me, private professionals had asked and informed parents that I would be contacting them. In all cases agreement to participate in the study was granted over the phone. After providing details about the study and their involvement, some parents asked me to call back at a later date so they could think over it and discuss it with the other parent. Others granted access straight away and fixed a time and date for the interview. There were a few parents who chose not to participate, usually motivated by time constraints or one parent not being supportive of the study.

With private specialists there was no need to negotiate access. Based on a brief description of the study over the phone, they were happy to cooperate and answer any questions.

Conducting the interviews

The interviews with school staff were held at the school, with specialists at their workplace and parents at their residence or at a café. As the majority of the appointments had been made on the phone, on meeting the introductory letter about the thesis was first presented and permission was obtained to record. The introductory letter also clarified informed consent, confidentiality

and right to withdraw, which was also reinforced verbally. The interaction began with informal conversation about general topics as well as clarification about the study and what was expected from the informants.

As suggested by Arksey and Knight (1999) I began the interview with easy to answer factual questions, for example I asked the principals when the school was founded and by whom. This was followed by open-ended questions, after which the lead was taken from the interviewee and an informal and continuous flow was maintained linking the various themes together. Each interview thus took a unique shape based on participant responses. The interviews were held in English, Hindi and/or Bengali and varied in length from 20 minutes to 2 hours. Parent interviews were considerably longer than those with school staff and specialists. The tone of the interview and the language was adapted to the person being interviewed. After the recording was stopped a short period was spent making casual conversation during which informants often returned to issues relevant for the study.

When I approached the informants I usually referred to the interview as a talk or discussion to understand their side of the story. This I feel minimized the formal nature of the interview and informants spoke openly and freely. Further, trust was developed in the interview by sharing information about myself. Informants were curious to know more about my background, why I was living in Sweden and interested in this particular field. Thus in many cases the interview started by them interrogating me and laid the ground for trust and openness during the interview.

I did not feel recording in anyway distracted the informants or influenced the quality of the conversation. With the exception of two principals who expressed initial hesitation regarding the recording of the interview, the others did not require much reassurance. During one interview a principal asked me to switch the recorder off for two minutes when she mentioned sensitive personal information regarding a parent. Further, interviews with two teachers were carried out in a classroom while the students were on recess. In this situation it was not only thought inappropriate but with the level of noise not so useful either. I noted key words and verbatim comments and elaborated on them immediately after the interview.

Even when the interviews were recorded, I wrote down occasional phrases to remind me of follow up questions, points to return to or key issues that required clarification. Informants frequently switched topics midway to share other insights that were triggered during the conversation, often leading to

other valuable information. This re-affirmed their level of comfort during the interview and I did not interrupt them, instead returning later if possible to the issue that was left incomplete.

Conducting classroom observations

As mentioned previously, classroom observation was an important part of data production. In total I had about 70 hours of observation. I had not met the class teacher prior to the observation. It was the special educator, counsellor or another teacher who met me at the gate and guided me to the classroom. On my first day observing in the field I was taken into the classroom by a special educator. In hindsight I realized it was not the appropriate thing to do, as in this case the special educator worked occasionally with the child and he later asked her if I was there to observe him. Following this I made it a point not to knock on the classroom door with a special educator or counsellor.

Unlike Singal's (2004) account of her challenges faced with teachers, the teachers in my study were friendly and cooperative. The class teachers had even given some thought to where it would be best for me to sit, prior to my arrival. The placing often gave me a good view of the child in question but without it being too evident. A few teachers gave me an option to change my seat on the second day. With the exception of one school where there was no vacant desk and chair, I sat with the students usually towards the back or one side of the room.

A non-participant observation approach was adopted and I maintained a low profile in the classroom. The exception to this was when teachers invited me to join the conversation in the classroom. For example, during a General Knowledge lesson, the teacher requested me to ask the students a few questions about Sweden. In a few other schools I was asked to share during a lesson what it is like to live in Sweden. Further, some students often interacted with me during recess or in between classes.

Through the day I followed the students in the class across various school settings and activities. During this time I maintained a descriptive narrative account with attention to the general happenings in the classroom, with particular attention to areas highlighted in the observation schedule. Comments that were of significant interest were noted verbatim. I followed Fangen and Nordli's (2005) advice and maintained a detail description of events without

including any value judgments. Any personal impressions or thoughts on analysis were clearly bracketed to keep it separate.

No names were mentioned in the observation notes and instead letter combinations were assigned to the teacher and the children. My handwriting in general is illegible, which according to Delamont (2008, p. 47) “affords the researcher some privacy” On one occasion a teacher came up to me during recess to ask if I would like a cup of coffee. Then she commented on what could be so interesting for me to write down and suddenly picked up my notebook and flipped through it. However, apart from a sketch of the class plan little else caught her attention.

A typical school day started between 7.30-8.30 a.m. usually followed by assembly. The assembly was conducted by the principal or department head. A number of classes came together during assembly, there was usually a hymn sung, prayer said, important information provided and acknowledgement of those who had received any significant recognition or award outside school. The day was then divided into 35-45 minute lessons and there were 7 to 9 such lessons in a day. Academic lessons were interspersed with other activities like music, art, craft and physical training. There was either one long recess or two short breaks where children usually decide what they wanted to do. The majority ate a snack or lunch and went out to play. Some chose to stay in the classroom. The school day ended between 1:30 and 3:00 p.m. A sample timetable is included in Appendix 1.

Data analysis procedure

Transcribing the data

As a first step in preparing the data for formal analysis, the recorded interviews were transcribed. I followed Kvale and Brinkmann’s (2009, p. 180) advice and started with the question “What is useful transcription for my research purpose?” to guide me through a series of choices that had to be made regarding the level of transcription detail needed for the study. While the explorative nature of this study made it challenging to know what data could be significant for the analysis, there were sections in the interview that were clearly irrelevant for the purpose of this study. For instance, description of the interviewer’s background, changes in the city of Kolkata, details regarding the extended family and interruptions during the interview. Thus decisions re-

garding relevance selectivity were made continuously during the transcription process.

The interviews were not transcribed verbatim, as the intention was not to make a discourse analysis but to transform the interview into coherent readable form, to assist in communicating meaning of subjects stories (Kvale & Brinkmann, 2009). This led to excluding repetitions, pauses, peculiarities of speech (eg. mhhh, ahhh, 'you know') and adding punctuation. Moreover, despite transcribing into a formal written style, an attempt was made to maintain the colloquialism used by the participants (e.g., copy for notebook used, tiffin for lunch break). Having been brought up in a similar context, these words reflected school life for me, making the transcriptions feel alive and aided the process of analysis. However, at the final stage when certain extracts were chosen to explicate themes in the articles, these were rendered readable for the audience in question.

Finally, as the interviews were conducted in three different languages, transcribing also required choices regarding translation. A decision was made to translate all interviews to English while transcribing, as English was one of the languages required for publication of articles, as well as submitting the thesis. While translating the emphasis was on meaning and not literal word translation. However in cases where the used word conveyed something that was impossible to translate, it was transcribed in Hindi or Bengali. Moreover, it was noted if a particular English word (e.g., the word 'normal') was used in an interview where there was a predominance of the Bengali and/or Hindi language.

Organising the data

The study generated a large amount of data, which included interview transcripts, school observation notes, field notes, research diary and observations during workshops. Pseudonyms were assigned to individuals, as well as schools. After which the data was sorted and organised using NVivo qualitative data analysis software which increased the manageability of the research and provided a comprehensive picture of the entire body of data. At this stage the type of data structured the organisation within NVivo (interviews, observations, field notes, research diary). These were then divided into sub-categories, for example interviews were dividing according to role of the

stakeholder i.e. parent, principal, teacher, special educator, counsellor and private specialist.

While the data was coded manually in NVivo, the software was also an important aid to analysis and offered a number of advantages. Extracts with the same code were grouped together, with a link with information regarding person and/or school, clicking which led to the interview and the context of the extract. This ease of switching between isolated extracts to the whole was useful during analysis. This also aided in providing a snapshot of the stakeholders represented within a theme. Moreover searching for words and phrases within and across interviews was made easy with NVivo. Due to personal reasons I had to take a long pause during the analysis phase of the data and returning to the process was made easier with data and codes organised and sorted in NVivo.

Analysis process

The first step was several readings of the entire body of data to gain familiarity. As all the interviews were transcribed by me I was already closely acquainted with it. Thoughts arising during this process were noted as memos (see p. 65). The data was then analysed inductively but also drew on an ongoing reading of existing literature. The approach to analysis adopted Hammersley & Atkinson's (2007, p. 163) advice:

...analysis cannot but rely on the existing ideas of the researcher and those that he or she gets access to in the literature. What is important is that these ideas do not take the form of prejudgements, forcing interpretation of the data into their mould, but are instead used as resources to make sense of the data. This requires tolerating uncertainty and ambiguity and resisting the temptation to rush to determinate conclusions. In the early stages the aim is to use the data to think with. One looks to see whether any interesting patterns can be identified; whether anything stands out as surprising or puzzling; how the data relate to what one might have expected on the basis of common sense knowledge, official accounts, or previous theory.

A broad analysis was conducted across data sets. More concretely, first and second cycle coding methods and analytical memos guided the analysis (Saldaña, 2009). To begin with first cycle coding through 'open coding' (Neuman, 2003) was carried out which primarily involved holistic and descriptive codes, to organise and condense the large amount of data generated through the study. These themes were at a low level of abstraction and were

guided by my “initial research question, concepts in the literature, terms used by members in the social setting, or new thoughts stimulated by immersion in the data” (p. 443). Coding was initiated with school staff interview transcripts, after coding a few interviews, linkages among different codes became visible which I started grouping together under certain headings. Certain themes stood out early in the analysis, like inclusion related, peer related, child strengths and weaknesses. On extending the coding to private professionals and parents, new codes were developed. Regularly the codes were looked through to see if they could be merged or organised differently. This was followed by second cycle coding termed by Neuman (2003) as ‘axial’ and ‘selective’ coding. This involved linking the initial codes and themes to identify the cluster of ideas, concept and organising themes.

As themes started emerging, I looked for both trends across schools, as well as patterns, similarities and differences within each stakeholder group. In addition, for the seven schools that I had complete data sets (interviews with school staff and parents, as well as observations in the classroom), I tried to access for within case analysis. While the intention of the study from the start was not to undertake a case study approach, it still became a powerful lens for beginning to develop a nuanced understanding of each school. Moreover, while doing so I became aware of the fact that these themes were shared across the schools. This led to the conclusion that by doing an in depth analysis of just a few schools would not provide as rich an exploration as across the different schools.

Subsequently I identified themes that went across two or more stakeholder groups. The terminology of ‘inclusive education’ was one such in relation to principals and special educators that then became the core of Article I. A theme that went across all stakeholders groups was how they perceived the child with autism and his/her needs. Interesting similarities and contrast were visible between stakeholder groups, which led to this being developed further in Article II. While parents provided certain insights into classroom practices, their unique position external to the school resulted in certain themes that were particular to them. At this stage of the analysis themes regarding the decision making of parents of getting the child into school and supporting his educational needs surfaced strongly, resulting in a focus on parents in Article III. In this study understanding teachers’ practices within the classroom were central. Visible in the themes were the wide variation in their perceptions and

practices but even fundamental similarities, which was made the focus of Article IV.

Subsequently, for further analysis in each article the existing codes and themes were extracted. At this stage the focus was on second cycle coding (Saldaña, 2009), keeping in mind the particular research questions addressed in each specific article. This involved scanning the data and previous codes, focusing on major concepts developed through the study and searched for deeper patterns and connections within such themes (Neuman, 2003). The analysis was a cyclical act where I continuously moved between the different coding cycles, recoding, re-categorizing and as well returning to the transcripts to follow new leads. Leading from the postcolonial critique of disability in the South, permeating the analysis was sensitivity towards the possible tensions, contradictions and dilemmas inherent in the data. Each article elaborates on the specific details of the analysis process.

Worth mentioning is a factor that played a central role in the final stages of the analysis. After taking a long break in the study for personal reasons, I returned to the analysis with a fresh lens. Having distanced myself from the data, gave me the ability to take a step back and look abstractly at the data. Further, at this stage I was exposed to the wider field of schooling within which I started to locate the findings from my study and seeing the bigger connections, which further impacted the analysis and the form the articles took.

Analytical Memos

Memos were central to the analysis and its application in this study aligned to Clarke's (2005, p. 202) description, "memos are sites of conversations with ourselves about our data". Early ideas, assumptions, reflections and emerging patterns that came to mind during the process of reading, coding or analysing the data, were immediately noted in a memo. The size of these memos ranged from a few lines to longer extracts. NVivo provides the option of linking memos to specific dates, nodes, or other sources of data, which benefitted the analysis. Moreover these memos could also be coded and categorized. Below are two examples of memos.

Memo: 2010-08-10 11:03

What this parent says is interesting in connection to what has come up in the other interviews, particularly in schools and with specialists. There

seems to be a concern over the transition period- some say junior to middle school others primary to senior but it is usually described as around class 5-6. The reasons provided have been different-there is not only change in the level of academics and abstractness but also in peer understanding. All children go through significant changes during this time, making the child with autism's behaviour seem odd. Have to follow up this line of thought. Seems to be a crucial turning point and hurdle. Maybe there should be a node on transition. I have coded references made to this but I wonder which node I have placed them under. Could it possibly be inclusion to a certain level?

Memo: 2011-07-27 15:07

The more I read through the data, the more I wonder if even principals who employ special educators know what role they expect them to play in the school, leave aside teachers. Is it to handle any difficulties that arise in relation to special child? Is it to provide the extra academic input? Is it to be an extra hand in the classroom? Or is it just to satisfy the principal's conscience that they are doing all they can for the children with special needs in the school?

Ethics, reflexivity and methodological dilemmas

The planning and conducting of this research has been guided by the ethical principles for research in the humanities and the social sciences adopted by the Swedish Research Council (Vetenskapsrådet, 2002). These principles place four general demands on a research study with the aim to protect the individual: confidentiality, consent, information and the use of the data. I discuss here how these were practically put to application in this study. 'Information' means that the researcher has to inform the participants in the study about the purpose of the research, how it is to be conducted, what it will contribute to and how the research results will be used. Further, information regarding voluntary participation and possibility to withdraw their involvement in study at any point should be provided. During the first contact with stakeholders either on the telephone or in person, the aforementioned was communicated. Moreover, this information was also provided in written form to all participants, individualized according to their role and complemented verbally before commencing the interview. Included also in the introductory letter was information regarding the researcher, my background, institutional affiliation, contact details (in Kolkata and Sweden) and if participants showed an interest a letter from my supervisor, including her contact details was shared.

The demand for consent refers to participants independently deciding if they choose to be involved in the study, without any external pressure to do so and the possibility to withdraw at any stage. This was obtained directly from the parents, specialists and in the case of schools from the principals. I will return to the consent of teachers, special educators and counsellors later in this section (see p. 72).

The demand for confidentiality has been an important concern in this study. All the material gathered has been only processed by the researcher. Various measures have been taken to make it difficult for anyone to identify a particular person or school in written publication, as well as oral presentations. Prior to transcribing, pseudonyms were assigned to schools and participants. However it is not only names that can disclose the identity of a person or school, but other additional details. Weighing the value of the detailed information regarding participants and schools, versus the negative consequences for those involved, I have chosen to eliminate certain identifiable details. I have not distorted any information but provided it in such a way that it would be difficult to identify the person or school, for instance using a range of years and a not a particular number of years a private specialist has been working in the field and eliminating certain identifiable details like school fees, curriculum details which along with founding year would make school identification easy. In addition, inconsequent use of sex of the child and double anonymization particularly in articles has been adopted keeping in mind the sensitive nature of the study and the small sample. Finally, communicated in the information letter as well as orally was how the information regarding the data from this study was going to be used only by the researcher for research purposes and the results published and presented in form of a thesis, articles other publications and oral presentations.

These ethical principles are not seen as replacing the researchers own judgment and responsibility, which is emphasized in the above document as well as its successor the report titled Good Research Practice (Vetenskapsrådet, 2011)²². Similarly Guillemin and Gillam (2004) draw attention to ‘ethics in practice’, which involves identifying and responding to situational dependent circumstances and ethical contingencies that can arise in the

²² Good Research Practice was published after the commencement of this study, and is now recommended to be used instead of the ethical principles for research in the humanities and the social sciences. The intention is to alert researchers to ethical issues and problems, stimulate thinking and reflect on the responsibility and challenges in conducting research.

processes of research. This they say can be achieved through ethical reflexivity “a continuous process of critical scrutiny and interpretation, not just in relation to the research methods and the data but also to the researcher, participants, and the research context” (p. 275). Keeping these in mind I chose to follow the advice of (Beach, 2010, p. 125) and “locate ethical decisions as internal to the research process itself, linked to the everyday interactions and ongoing research activities, rather than a set of principles established external and prior to the conduct of the research”. Further, this grounded approach was relevant for my study that was conducted in the country of my origin but a context that was different from the one where my research training took place. Supporting this, Vulliamy (1990a, p. 112) stresses that while ethical principles might alert researchers in developing countries to ethical problems but they can only be resolved by ‘individual conscience’.

However, what is even more important is that there is a growing body of literature questioning the adequacy of international guidelines, codes and principles for conducting research in countries of the South. Robinson-Pant (2005) highlights the apparent conflict in context of international students in Britain, who are compelled to follow the ethical guidelines prescribed by the university while conducting their research in the home country. Similarly Qureshi (2010) illustrates through examples from her research, how international codes adopted in Pakistan clash with socio-cultural norms within the country. Like many of the previous mentioned researchers, I too did face some conflicts between adhering to Swedish ethical guidelines and conducting the research ethically within the Indian cultural context. Some of these will be highlighted in the discussion below, where I reflect on ethical concerns, tensions and dilemmas that arose during various stages of the study.

Relevance of my research

Similar to my doctoral thesis, my Master’s dissertation was affiliated to a Swedish university but the research on ‘culture in adoption’ was conducted in India. The study was well received, the dissertation played a crucial role in my admission to the PhD program and I even published an article in a peer-reviewed journal. The results from my study were also presented in different contexts by my supervisor. However in retrospection, the question that perturbed me was the relevance of my research in the context where it was conducted. The questions were pertinent in Sweden and other countries of the

North, a central topic of discussion but of little value in India. This laid the foundation for my primary ethical concern prior to my thesis i.e. the relevance and purpose of the research for those in India.

A quandary that arose during the early stages of the research, in particular during the process of identifying the research questions and methodology was ‘what knowledge is relevant’ and ‘what is interesting’. As I am affiliated to a Swedish institution, it made it essential to balance feedback from my supervisor, tutors and peers in the department as to what they thought would be a knowledge contribution, interesting to research and how, with the real concerns embedded in the context of India. Similar dilemmas of international students have been raised by Robinson-Pant (2005), where she highlights issues like ‘whose knowledge to contribute to’ and the influence of the supervisor’s frameworks and beliefs in designing the research. This brings to the forefront concerns on the need and legitimacy of the research and for whom. The importance of the research study benefitting the communities where the research occurs is now been frequently raised in context of researchers from the North conducting research in Southern contexts (Robinson-Pant & Singal, 2013).

While in the early 1990s Vulliamy (1990b) raises the importance of disseminating findings from the study in relevant national contexts, two decades later Robinson-Pant and Singal (2013, p. 421) raise how ethics of dissemination continues to receive little attention. They highlight a gap in the ethics discussion where “there is no explicated stated obligation to disseminate the research. It is often left to personal desire and motivation of researchers to publish their work or not, even when it is funded through public research money.”

How and where to disseminate my findings were reflected on early in the research and is an ongoing endeavor. As a first step, a conscious choice was made to do a thesis by publication, where four articles were generated as part of the thesis. Moreover, where to publish was given significant thought, where obtaining a balance between university regulations, appropriate audience, generating academic discourse and doing justice to the rich data were central. Moreover, I identified journals where research from an Indian context had been published. The choice of journal for each article has been carefully made, motives for which are accounted below.

International Journal of Inclusive Education was perceived as having readership from the North and South and an ideal place to publish a critical article

on inclusive education. The International journal of Disability, Development and Education was chosen for the article on autism awareness and perspectives as it has significant Southern readership. Contemporary Education Dialogue, the only peer reviewed education journal in India was seen as appropriate place to publish the article focused on parents. The intention was to include disability education into mainstream educational research within the Indian context, as well as make visible voices of parents on education, which finds little representation in this journal. Moreover publishing within this journal will have maximum reach within Indian.

Daley, et al. (2013) discussing autism research in low and middle income countries, stress limited access in these settings to so called prestigious expensive journals in the North, which they argue should be only one of the mediums through which findings are disseminated. In concordance with Robinson-Pant and Singal (2013) they propagate for dissemination in format accessible to various stakeholders and through appropriate sources. Reaching out to different stakeholders through various mediums by presenting at national conferences, schools and writing in non-academic journals in the national context, is something which I have initiated and will continue after completing the thesis. Moreover, post publication of the accompanying articles an attempt was made to reach out to the relevant audience through Facebook, Research Gate and LinkedIn through the 50 free copies provided by the journal. In addition, individual mails to people working in the field were sent.

Local research culture

In the past ten years a number of qualitative studies have taken place but dominance in research in India has been through surveys and quantitative market research. Hence the little exposure if any participants have had to research is connected to questionnaires. Many of the principals mentioned that their teachers did not have time for research and filling in questionnaires but they had no objection to me interviewing and speaking to the teachers. Even within the classroom, teachers wondered how talking to them and observing in the classroom could be of use for a research. With this backdrop using interview was to my advantage, it has helped me to gain access and obtain rich information. Similar experiences have been reported by Pillay in her doctoral research in Malaysia where she described the unfamiliarity of participants to qualitative research methods, making them less conscious to revealing infor-

mation through interviews in comparison to questionnaires (Robinson-Pant, 2005).

However this raises a few ethical dilemmas. Did participants really understand how the information obtained through interviews and observations could be used in research? This brings to question the principle of informed consent. Dilemmas around informed consent have been discussed in depth by Asif (2010) in context of rural Pakistan. While my study is conducted on educated, well to do participants in urban India, the concerns are similar. Could I really say that all those who had consented to participate in this study were really ‘informed’? Did they understand what they had consented to, despite my verbal and written information? Had they understood the objective of the study? My personal impressions from many of the interviews were that participants appreciated the opportunity where someone was interested in listening to them or a sounding board, rather than perceiving it as data for research. This contrasts with the different research culture in countries like Sweden and U.K. where school staff is frequently exposed during their education and work to qualitative and quantitative research and have a different understanding of the impact of what they say and do in a research study.

An additional dilemma was whether by adopting an informal relaxed approach during the interviews, more like a conversation, strengthened the participants’ illusion of it not really being research. However this approach of interaction is so embedded in the Indian culture that for me it was a natural way to build rapport and conduct the interview to obtain quality data.

The ethical principle of confidentiality also posed certain concerns. Interestingly, when I stressed on confidentiality before the interview, with the exception of parents many participants did not express any concern, for instance a private specialist stated “This is what I think and if you want to write my name I don’t care”. Despite Kolkata being a large city there are limited professionals working in the field of autism and a few schools with an inclusive mandate which make it difficult to provide total confidentiality. This was discussed with them, a head of a school with an inclusive mandate said, “This is how we do it and we are proud of it, so it doesn’t matter”.

As highlighted in many of the examples raised by Robinson-Pant (2005) the trust in the researcher makes it the researcher’s personal ethical responsibility to balance participants lack of understanding of research and unfamiliarity with ethical rights, to actual socio-cultural differences, advice that I have taken heed off. Thus keeping in mind the local research culture and the

possible inability of informants to see the consequences of it, have led to my prioritizing the confidentiality of participants, at the cost of some participant details (for discussion see p. 67).

Power differential

Asif (2010) discusses two types of ‘relational vulnerabilities’ one connected to research participants consent and the other to the role adopted by the researcher in the field. I discuss both these further in relation to ethical concerns I had arising from unequal power relations between some of the participants and me.

All parents had been asked by a private specialists if I could contact them, my apprehension was that they might feel compelled to participate, which I found was not the case as some did refuse. Secondly, many of these specialists provided therapy or parental support, thus making it a concern whether parents would be open about their child’s education and schooling, which could be related back to advice from these professionals. However, during the interviews parents mentioned both positive and negative experiences with the same specialist.

In schools a similar power differential was anticipated in relation to teachers, special educators and counsellors. They had little say in whether they would like to participate in the study as permission had been granted by the principal. However, when I did approach teachers requesting to talk to them, none of them expressed that they were compelled to cooperate. It was an individual decision and lack of time seemed to be more of an issue but they all accommodated me.

The disadvantages of the researcher being viewed as an ‘expert’ or a ‘critic’ has been discussed by Hammersley and Atkinson (2007) and was also a concern. The likelihood of unequal power relations between the participants and me, based on the fact that I was the researcher, questioning and observing them and coming from a foreign university. In connection, the authors stress the significance of the roles the research adopts in the field to create the impression necessary to gain access as well the necessary data. The information letter strategically positioned me first as an insider, an Indian, with strong roots in the city and with links to the autism community in India. To be followed by acknowledging my outsider status and affiliation to a university in Sweden. Being an insider-outsider simultaneously is supported by Lofland

(1971), as a balanced approach to obtain participant perspectives but also minimize dangers of over rapport.

Moreover, I strategically positioned myself differently with each group. With principals I particularly emphasized my Swedish credentials and researcher role to negotiate a first meeting. In contrast with teachers I adopted the role of inquisitive young person and with counsellors and special educators I took the role of a peer. As for parents, I stressed my familiarity with the field of autism, having trained at the National Centre for Autism in Delhi and an empathetic listener. Finally, private specialists' perceived me as a curious student from Sweden trying to do a research in the area of schooling for children with autism that many of them were passionate about but had limited influence on.

Two way relationship: give and take

In line with Walford (2008b) I developed a reciprocal relationship in schools and with other participants (see p. 58). However a continuous ethical dilemma was when to draw the line, as in some cases I was asked for assistance on issues that I felt were either impossible or inappropriate. For example a principal wanted me to help them establish contacts with schools in England and Sweden, so they could obtain funds for having international contacts. A similar situation arose with a few parents. As some parents had negotiated entry to the school, they were vocal about getting something in return. One parent explained that she had gone out of her way to convince the school, which was usually skeptical to allowing outsiders to be in the class. She justified that she or the private specialists associated with the child had not been allowed previously and wanted me to be the 'inside eye', to tell her what was happening and to provide tips on what could be done in that situation. This led to an ethical dilemma as I had affirmed confidentiality to the school. I spoke to the principal about this and she said it was fine to share with the mother any information that would benefit the child managing in class. I was however very careful about what I said and restricted it to concrete issues that were closely related to the child or peer interaction rather than to the teacher.

Moreover, informants were curious about my private life. Hammersley and Atkinson (2007) have discussed issues around how appropriate or fruitful self-disclosure is and for me this raised an ethical concern of how much I should be sharing. On reflection I realized how it seemed inappropriate in the Indian

context not to share information about myself when participants like parents were being open about their lives and sharing intimate details. I thus decided on a two way exchange where I answered questions among others about how I met my husband, my plans about starting a family, my relationship with in-laws and life in Sweden.

Issues of confidentiality of the child with autism

A central ethical concern during classroom observation was not revealing the purpose of why I was present in the classroom to the students, including the child with autism. Not only did I consider this essential for the well-being of the child but it was also emphasized by many parents. I communicated this to the person I was in contact with at the school, explaining that the teacher should not introduce me to the students in a way that made it obvious why I was there. Thus the class teachers often introduced me to the class as “Ms. Johansson has come from Sweden and is spending time in different classes” often adding “she has come to see how smart you are and how well you work”. The latter I could not avoid.

However, there were in some cases conflict between the confidentiality of the child and informed consent of teachers. As not all subject teachers had been informed of my visit, I had to explain this to them when they entered the classroom for their specific lesson. My initial experience was while some understood the importance of being discrete others failed to adopt this approach. Thus I put the confidentiality of child prior to informed consent of these teachers, I initially said I was a visitor from Sweden and waited till after the lesson was over to explain in detail why I was there, obtain their consent and a short account of their experiences.

5. Summary of the articles

This chapter provides a summary of the four articles accompanying this thesis. As in chapter 4 a detailed account of the methodology was provided, the article summaries here are limited to highlighting the focus of the article, the specific data drawn on, the main findings and conclusions.

Article I.

Taneja Johansson, S. (2014). A critical and contextual approach to inclusive education: Perspectives from an Indian context. *International Journal of Inclusive Education*, 18(12), 1219-1236.

Post Salamanca, inclusive education was incorporated in government policies in countries of the North and South. Since then there have been numerous books, articles, and academic debates on the topic but with little representation from the South. This article examines how inclusive education is conceptualized in India, within four recent government policies and in practice. The analyzed policies pertain to inclusive education and/or children with disabilities, and have been adopted during the last decade. The school-based data draws on interviews conducted in 11 schools with 13 principals, 8 special educators and 3 counsellors.

The findings suggest that in the last decade there has been further entrenchment of the inclusive education discourse in India. This is visible in the increase in the number of policies that incorporate inclusive education and the frequent use of the term even among private fee paying schools who are not obliged to follow government policy. While there seemed to be a consensus in policy and practice on the ‘goodness’ of inclusive education and it being synonymous with children with disabilities, there were multiple meanings assigned to inclusive education. For instance, a semantic confusion visible in the analysis of the government policies was how the words inclusion and inclusive education were used for distinctive purposes. The term ‘inclusion’ was broadly used for all children and concerned inclusion into the education system, whereas ‘inclusive education’ was a type of program offered to children with

disabilities to support their presence in mainstream schools. In contrast, school staff used the words inclusion and inclusive education interchangeably.

Findings highlight how adoption of inclusive education in India has also led to the conceptualization of an 'inclusive school'. Across policy documents and in the field, 'inclusive schools' were designated as one type of school among others (such as mainstream schools, special schools) but their use and description varied. Moreover, while the word inclusive education in government policies and among schools concerns predominantly children with disabilities, findings highlight how it was actually about some children with disabilities who were considered suitable for a mainstream school.

Another interesting finding shows how unlike previous studies on private schools (see Jha, 2010), the presence of children with disabilities in the schools in this study were not acts of altruism. While newer schools were found to be admitting the child with autism driven by the economic imperative to establish the school in the market and increase enrolment, in the remaining schools it was a result of unawareness of the child's problems prior to admission. Despite variations in how children with autism gained admission, there were similarities in principals' acknowledgement of their responsibility for these children. Old and new schools alike emphasized the well-being of the child but in practice this seemed to be expressed by making small adaptations. Nonetheless, what this finding shows is a growing culture of consciousness of responsibility among private schools.

The article then discusses how despite the term inclusive education being well anchored in India, certain fundamental discrepancies continue to pervade the inclusive education discourse, namely, what is inclusive education, who gets included and where. While these findings reaffirm the inconsistencies surrounding inclusive education as highlighted previously by researchers (Hodkinson & Devarakonda, 2009; Julka, 2005; Singal, 2006a, 2008), the dissonance was found to be more obvious today. Variations in conceptualization of inclusive education were visible not only between school staff and policy documents, but also between the different policies, even those generated within the same Ministry, as well as within the same policy. Based on these persisting ambiguities surrounding inclusive education, the article engages with the question, why after a decade the discrepancies encompassing inclusive education persist, with particular reference to Northern hegemony. It concludes by arguing for a contextualized understanding of how education of

children with disabilities can take place in India and for a more critical stance towards inclusive education.

Article II.

Taneja Johansson, S. (2014). "He is intelligent but different": Stakeholders' perspectives on children on the autism spectrum in an urban Indian school context. *International Journal of Disability, Development and Education*, 61(4), 416-433.

This article investigates school staffs' awareness of autism, which includes people having simply heard about autism, to their knowledge and understanding of the various educational and social conditions associated with the diagnosis. It also explores stakeholders' perspectives on children with autism. The focus was on how stakeholders understood the child with autism in mainstream school and included a description of the child, his/her strengths, weaknesses, educational needs and difficulties in relation to school. It draws on interviews conducted in 11 schools with 13 principals, 11 class teachers, 8 special educators and 3 counsellors. Additionally, 18 parents and 11 private specialists were interviewed.

The findings indicate varying but limited awareness of autism among school staff. While principals were familiar with the term autism, their understanding was restricted to autism as a severe condition rarely present among mainstream school children. Special educators and counsellors linked autism to areas of difficulty, mainly autism as a language and/or communication disorder. However, only two special educators could explain in what way these difficulties influenced a child's functioning in school. Moreover, evident among them were numerous ambiguities in their knowledge about autism. When it came to teachers, only 2 out of 11 had briefly heard the term autism prior to being informed about a child with autism joining their class. Nevertheless, teachers had shown little interest in trying to gain more information about it and the term autism continued to have little meaning for them.

The findings illustrate how teachers, counsellors, special educators and parents described the child with autism in significant detail without always connecting it to characteristics linked with the diagnosis or difficulties arising in the educational setting. Teachers rarely associated the child with having a disability, in their accounts they described the child as being 'different' by

raising behaviour characteristics and personality traits that differed from the peers. Moreover, parents, teachers, special educators and counsellors, regularly used the dichotomies 'not normal' and 'normal'. They felt that the 'not normal' odd behaviours were a contradiction to the 'normal' intelligence shown by the child. To place the child within the realm of normality, school staff as well as parents frequently emphasized intelligence, both in subject based learning as well as in general.

Another aspect highlighted in the findings is the challenges faced by the child with autism in school. Difficulties arising due to certain behaviours of the child were mentioned by all stakeholders. However, while parents and specialists gave detailed accounts of the likely connection between many of the odd behaviours and the child's social communication limitations, teachers' explanations were limited to more superficial factors. Interestingly, despite teachers' previous emphasis on the child being intelligent, their main concern was the child's academic performance, in particular academic assessments and written work. In contrast, private specialists raised the difficulties faced by children with autism in the social sphere, specifically social misunderstandings with others and teasing and bullying by peers. Stressing the significance of providing input to the child to develop social understanding, private specialists ascribed this role to parents. Parents raised both academic and social difficulties. In case of the later they resigned to the fact that they could not expect school to work on developing their child's social skills. While school staff was aware of the peers bullying and teasing the child, their intervention was limited to sensitizing the peers, with little importance given to helping the child understand the situation and develop the skills to handle it.

Drawing on Minow's (1990) 'dilemma of difference', the assumptions underlying teachers' accounts of the child being different are discussed, in turn highlighting how the knowledge of the child being different did not lead to differential response. Teachers emphasized the child's educational needs arising out of academic difficulties, which are not dissimilar for what they would have done for the child's peers. Consequently this resulted in personality and behaviour differences being disconnected from the educational needs of the child. Having little awareness of autism, teachers did not recognize how characteristics associated with autism played a central role in the child's behaviour and academic performance, a view frequently reinforced in the interviews by parents and private specialists.

While increasing teachers' autism knowledge might lead to increased awareness and acceptance, findings from this article question whether the needs of these children would still be met. The article argues for the need to delve deeper into assumptions embedded in the Indian education system. Despite the fact that stakeholders had different relations with children with autism, and different experiences that shape their understanding they were all located within a society where there exists certain central beliefs regarding education and the appropriate knowledge to be taught in school. This resulted in the consensus among school staff, private specialist and parents on schools role as limited to academic learning. These findings are connected to the wider discussion of quality of education in India.

Article III

Taneja Johansson, S. (published ahead of print). Parents negotiating change: A middle-class lens on schooling of children with autism in urban India. *Contemporary Education Dialogue*, 13(1).

This article aims to explore the views and experiences of schooling among parents of children with autism from middle income families in urban India. It specifically focuses on how parents choose a school, what interactions they have with the school, and what key issues they highlight with reference to their child's schooling. Eighteen parents with children attending private mainstream schools in Kolkata were interviewed. They were parents of nine boys and four girls, aged six to 12 years and attending class one to seven.

The findings position parents as strategic agents who actively negotiated a range of dilemmas and tensions to ascertain their child's admission in the school. They were cognizant of the available choices for their child in the private schooling market and acted strategically in terms of where they chose to apply and what information they provided, to ensure admission for their child. While parents were at the face, positive about the school their child attended, their descriptions actually show how schools had not made any significant changes to accommodate to the needs of their child. Parental expectations from school were clearly limited to the school supporting their child through the formal assessments and examinations, which they perceived as essential for the child's progression through the school years. Interestingly, they did not

expect the child to learn in school. Learning was viewed by them as their responsibility and carried out at home.

The findings also indicate how parents shared a precarious and fragile relationship with the school. As the schools knew about the medical diagnosis there was always the possibility that they could ask the parents to remove the child from the school. This fear made the parents indebted to the school for allowing, accepting and accommodating their child in the school despite his/her problem. Nonetheless, while parents overtly seemed grateful and expressed an unquestioning attitude, they exerted agency in a strategic manner. The analysis showed that parents were actually proactive, judging the situation and progressively pushing the boundaries set by school at opportune times to ascertain their child's continuity in the school. These included among others when to disclose the problems or diagnosis, ask for extra support, reduce the amount of syllabus the child has to cover as compared to peers and approach the subject of employing an assistant for the child.

Illustrated in the findings are how parents' key concerns regarding their child's continuity in the school were the transitions that took place from grade 6 onwards. Parents drew attention to the increasing academic demands in higher classes and the widening social gap between the child and the peers. In addition, parents' perceived senior school teachers as not only having less time and an increased academic focus but being in general less caring and supportive of individual difficulties faced by the children.

Beyond transitions, inflexible school norms were highlighted as another obstacle for the child. Parents explicated that evaluation in school was not always about knowing the subject matter but displaying it within expected norms, for example in a specific written format. Despite these concerns, towards the end of the interview when parents were specifically questioned about what ideal changes they would like to make in the school for their child, it is interesting to note that they did not provide elaborate areas of development. There was an expression of forced recognition and reconciliation to the existing realities of the education system.

The article discusses how in many ways parents in this study were responding to the schooling of their child with disability in a similar fashion as other middle-class families in India, reflected for instance in their choice of private schools and alignment to existing tuition culture. Despite these similarities, findings illuminate how these parents of children with autism were doing something unique – they were actively creating a space for their child in

a private school not obliged to do so. In the process they were slowly shifting boundaries and putting up a resistance against the prevailing view among private schools of not educating a child with disability in the mainstream. Nonetheless, parents simultaneously contributed to the normalization of the larger education system by accommodating to the status quo in schools. The article concludes by reflecting on these complexities inherent in the findings and questions why these agentic middle-class parents who could be the impetus of greater change seemed rather limited in how they sought the school to change.

Article IV

Taneja Johansson, S. (manuscript submitted for publication). Teachers' responses to children with disabilities in mainstream schools in urban India: An autism lens.

This article investigates what factors influence teachers' practices and responses towards children with autism in mainstream classrooms. It draws on data gathered from 7 schools. This includes recorded interviews with 7 principals, 8 class teachers and 3 special educators, a range of conversations with subject teachers and approximately 60 hours of classroom observation.

Deviating from findings from previous studies on inclusion of children with disabilities in India (e.g., Das & Kattumuri, 2011; Parasuram, 2006; Singal, 2008), findings from this study show how teachers were positively inclined towards the education of the child with autism within the mainstream. Based on *their* understanding of the child, teachers were found to be making accommodations to further the child's participation within the classroom. The findings explicate how teachers adopted a certain amount of flexibility in relation to the child, specifically when it came to the prevailing norms on acceptable classroom behaviour, the procedure for assessment and examination and/or in the delivery of the curriculum. Moreover, teachers were found to be making reflective decisions on the best way to support the child. This was exemplified among others in their choice of where to seat the child, what behaviour of the child to attend to and what to ignore, and the frequent verbal inputs they chose to provide to the child during lessons.

Even though teachers seemed to take responsibility of the child and supported his/her participation in various ways, tensions arose when they per-

ceived themselves as limited by what *they* saw as expectations of the existing educational system, namely written work, assessment and examinations. Despite incorporating flexibility in these areas during their everyday practice, teachers perceived their primary responsibility to provide the child with autism, like other children in the class the essential skill of writing to enable them to pass the assessments and examinations.

Unlike the findings from research in the North (see for e.g., Lindsay, Proulx, Thomson, & Scott, 2013; Robertson, Chamberlain, & Kasari, 2003), teachers in this study did not emphasize autism as a category that needs to be understood to enhance their practices. Even though they acknowledged that the child had a special need, they felt that they had to judge and make allowances based on the child's individual differences within the realities of the larger classroom scenario. A reality where there is one adult in a class averaging 35 children, expectation on the teacher to fulfil the numerous tasks assigned to them and also responding to the diverse needs of the children in the class. Permeating teachers accounts was this dilemma on how to balance what teachers' perceived the child with autism needed, with the actual realities of their classroom.

The findings also highlight how teachers' practices in general seemed to be shaped by the norms governing being a teacher in India. For instance, their perceptions of their role and responsibilities in the classroom as a class teacher or subject teacher determined not only the efforts made by them to develop a positive relationship with the child but also the way they responded to the child during the lesson. Moreover, the seemingly common unwritten rule among teachers regarding non-interference on how to conduct their class, laid the ground for a total absence of collaboration between school staff regarding the child with autism.

A key factor determining teachers' practices was found to be the school principal. Principals made crucial decisions regarding, who to assign as a class teacher for the child with autism, the availability of a special educator and the limits of the possible accommodations that could be made for any child. However most importantly, the significance a principal gave to the participation of all children in school activities, in turn determined the effort and commitment made by the teachers specifically for the child with autism in that school.

Collectively the findings from this study show how teachers' practices were not being determined by only child related factors but by a range of environ-

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mental and cultural factors which were either positively influencing and/or limiting teachers' responses towards the child with autism.

6. Final discussion

This study set out to develop contextual understanding of schooling of children with autism in urban India, at a time where there is an increased focus on bringing children with disabilities into the mainstream classroom. To bring about change Fullan (2007) argues one has to start with the meaning and significance given to the change by the people who are the key participants to implementing that change. Similarly, Majumdar and Mooij (2011) claim that to improve the educational system one has to begin from the situation as it is and see the main actors involved as part of the solution rather than the problem. This was also the approach adopted in this study which took its point of departure in school staffs' and parents perceptions, experiences and practices, in educating children diagnosed on the autism spectrum in urban mainstream schools. Each of the accompanying articles have explored one piece of an infinite puzzle to start gaining an understanding of what is happening through a nuanced exploration of a variety of perspectives. By means of a situated analysis of the data, I have attempted to not only describe but also understand the strengths and struggles of stakeholders, their values and priorities, the paradoxes and tensions rather than adopting a deficit view on the educational system and its participants.

The traditional approach to a discussion chapter in a thesis is to bring together the various threads of the study into a cohesive narrative. It is about illuminating the findings, giving meaning to the results and putting forward the greater story. However, given the fact that not only is the field of special education atheoretical (Clark, Dyson, & Millward, 1998a) but even the theoretical perspectives that are present have originated and been developed from a strong northern perspective²³, I refrain from developing any such

²³. An exception to this is Artiles and Dyson (2005) comparative cultural historical framework, which is sensitive to local conditions and assumes that practices surrounding a phenomenon like inclusive education are mediated by culture and situated in a cultural-historical context. While on the surface it seems to have the potential to organize the findings from this study, I chose not to use it because of two reasons. Firstly, the framework has been constructed with a purpose to enable comparisons across countries. The comparative element is entirely absent in this study. Secondly, central to this framework is the historical component, which though partially implicit in all the operationalized contexts in this study has not been foregrounded in this study.

grand narrative on schooling of children with autism or disabilities in India. This approach also aligns with the conversations I have alluded to in Chapter 3, that we should not fall into developing a homogenic Southern voice, what needs to be respected is lived experiences within a specific context. Foregrounding the cultural, socio-familial, school and institutional contexts, has allowed me to illuminate certain aspects of the phenomenon and understand the complexities of how schooling of children with autism is taking shape in India. In keeping with the centrality of the notion of context in this study I draw on the metaphor of *space* to present and organize the findings.

Autism as it plays out in different spaces

Space is a geographical concept that has gained popularity in the social sciences and humanities in the late 20th century. While space is increasingly being discussed as an important dimension of social theorization, my intention of using space in this section is solely as a metaphor, that is a representational strategy²⁴ (for further discussion see Crang & Thrift, 2000). Certain attributes of space make it a particularly useful concept to organize, describe and explain the intricacies of the context as highlighted in the findings from this study. Space is essentially a socially produced construct, arising as a consequence of social processes (Gulson & Symes, 2007). Using this attribute of space, this section conceptualizes autism as a space for the medical, the political, the social and the educational. In developing contextual understanding of schooling of children with autism through an exploration of stakeholders' perceptions and practices, this study has in certain ways captured the aforementioned autism 'spaces' within the Indian setting. These spaces, as will be shown, cut across the various dimensions of context explored in this study.

Space also acknowledges the 'embeddedness of action in the world' (Crang & Thrift, 2000), that is spaces are part of other spaces, which in turn influence (not determine) what happens within a particular space. This characteristic of space is particularly interesting in relation to this study. Across articles, findings show that factors influencing stakeholders' perceptions and practices

²⁴ There is also geographical scholarship about space, place and disability (e.g., Soldatic, Morgan, & Roulstone, 2014) and a growing debate around space and place, within educational settings (e.g., Kerr, Dyson, & Raffo, 2014) but to reiterate it is used in this discussion as a metaphor to expand on the notion of a context.

were not always linked to the child with autism but other spaces within which schooling of children with autism was playing out.

Further, space is not simply the end product. Since it arises from social processes, it is always in process, which incorporates the aspect of time (Crang & Thrift, 2000). Thus space is not a given with distinct physical boundary, but varies in who inhabits these spaces and how these are constantly changing. This attribute of space provides the tools to be able to discuss both what the study has captured at one moment of time but at the same time account for the changes that are taking place in these autism spaces.

Thus, the metaphor of space as a social process encapsulates the contemporary, the historical duration and different geographical extents. Using these different attributes of space, this section discusses how the medical, political, social and educational spaces of autism have been illuminated by the findings from this study.

Medical space

Although the focus in this study was on children with autism, the medical diagnosis per se was not of explicit interest. The study started with children who already had been diagnosed on the autism spectrum and used this as a lens to explore their schooling. In similarity with any disability in India (see e.g., Singal, 2009), autism is strongly connected to the knowledge of the 'expert' i.e. the specialists who identify the problem, the limitations this entails and who then provide treatment, therapy and other interventions to compensate for it. This study assumed that this medical gaze was in place and that the autism diagnosis was constructed based on a medical discourse by experts.

Despite the fact that the diagnosis of autism has primarily been developed in the North, there has been little challenge to the notion of autism within India. In contrast both the validity and the relevance of the label have been subject to extensive critic in many countries of the North (Eyal, 2010; Moloney, 2010; Nadesan, 2005). While there is no such discourse within India that claims that autism as a label does not work or questions the international diagnostic criteria in place for autism, some researchers have raised the contextual and cultural nature of how the autism diagnosis and treatment takes place in India (Daley, 2004; Daley & Sigman, 2002; Grinker, 2008).

It is well acknowledged in reports and studies that information regarding autism in India is limited across all professional groups (Daley, 2004;

Krishnamurthy, 2008; Malhotra & Vikas, 2005; RCI, 2007; Vaidya, 2008). For instance, Daley's (2004) study on 95 children with a prior diagnosis of autism, in four cities in India, found that parents saw an average of four doctors some as many as twelve, before they received the right diagnosis for their child. Similar accounts were also narrated by parents in this study, who visited a wide range of specialists till their child finally received a diagnosis of autism. Understandably the concerns in India unlike the North are not about children being over diagnosed (CDC, 2010), but as the Rehabilitation Council of India report concludes, "despite increased awareness...many autistic children still do not receive a diagnosis" (RCI, 2007, p. 13). This is also reflected in Grinker's (2008, pp. 215-216) observation of the situation in India in his anthropological study on autism across cultures, "rather than concluding that there is an epidemic, many Indians conclude autism is a more accurate and useful diagnosis than mental retardation and madness".

In many countries of the North, key participants in the medical space are teachers and special educators within schools. This involvement of schools in the process of diagnosis has been subject to considerable critique and highlighted as one of the main reasons behind the increasing number of children receiving various neuropsychiatric diagnoses, including autism (Ekström, 2012; Molloy & Vasil, 2002). This does not seem to be reflected among the parental experience in this study. While three parents stated that a teacher had brought to their attention the difference between their child and the peers, only one suggested that the parents should consider consulting a specialist. Moreover, once parents did initiate the process to ascertain the cause of the problem, schools were never consulted during the diagnostic process. While under the government's SSA programme teachers are more actively involved in identifying children who might have a disability (Singal & Muthukrishna, in press), in case of a hidden disability like autism this is likely to be limited across urban and rural areas (RCI, 2007).

Further, it has been frequently shown that obtaining an autism diagnosis within the Indian context is clearly parent dependent and driven (Brezis, et al., 2015; Desai, Divan, Wertz, & Patel, 2012; Grinker, 2008). This is also supported by what parents narrated in this study. This is interesting in relation to the general discourse in the medical space being associated with the authoritarian expert and the passive parent.

To conclude, while the medical space remains largely uncontested, this is not the focus of this thesis. What is really interesting and comes out power-

fully in the findings from this study is how other spaces, as in the political, social and educational are changing in relation to not just autism but the broader field of disability. The following highlights some of the constructions and reconstruction of these spaces that are taking place.

Political space

Illuminated in the findings were the various ways in which the autism label was being deployed by stakeholders to achieve a certain purpose. For example, majority of the parents withheld information about the diagnosis of their child at the time of school admission. Parents clearly perceived that the autism label put their child in an unfavorable position to gain access to the school. By not disclosing the diagnosis, they tried to maximize the chance of entry for their child into the private school of their choice. Their underlying motivation for this calculated approach finds support in Daley's (2004) study, where parents described the autism label as being a hurdle to accessing educational opportunities for their child due to the widespread misconceptions of children with autism as 'unmanageable'. Similar understandings of autism as a severe condition were reflected among principals in this study.

This political use of the autism label was also visible in parents deliberate delivering of the information regarding their child's diagnosis to the school. This was done at a particular stage in the child's schooling with the intent to gain certain advantages, such as support, sensitivity and flexibility, which parents perceived was necessary for the child's continuity in school.

Schools were also found to be exploiting the autism label in order to not admit certain children in the school. While the two schools with an inclusive mandate highlighted the autism label of a child to show his/her unsuitability for their school setting, the other schools extended this beyond autism to a disability label in general to restrict entry. Interestingly, all schools justified this decision by emphasizing *their* inability to meet the needs of a child with autism, who would require certain special supports which these schools were unable to provide.

Not only was the disability label used by schools to deny entry to school for certain children but also as a reason to expel a child with disability. This was clearly articulated by one parent who had not disclosed the diagnosis to the school, "if they do not know about it, they cannot use it to throw him out". Drawing on the disability label, in particular autism to not admit and

exclude children from schools permeates media reports and has been shown in a previous studies (Narayan, et al., 2005).

This political use of the autism label is to some extent not surprising given that the whole discourse around disability per se is getting more politically charged in India. Disability has now transitioned from the sole focus on medical aspects to having other issues raised. This is pertinently highlighted by Jeffery and Singal (2008) who discuss how there is a growing awareness in India regarding the reservations and incentive provisions available through various schemes for people with disabilities. This according to them has resulted in people seeing the advantages of having a certified and identified disability. Their research experiences from a small scale study carried out in Madhya Pradesh, resonate with those of Pande and Dalal (2004) from a village district in Uttar Pradesh. In their study people were keen in being identified as disabled in the research with the intention of obtaining benefits, financial or other. This politicization of disability within India is an interesting development. Disability has transitioned from being solely associated with stigma which often resulted in families and individuals not disclosing the disability of a family member (Ghai, 2015), to actually wanting to identify a person with disability in the lieu of obtaining certain incentive provisions.

In many ways this politicization of disability in India is no different from findings from other parts of the world, especially where the diagnosis is well established and linked to allocation of resources (Swain, Gillman, & Heyman, 2000), through legislation or as result of other situational factors. An interesting case in example is Isaksson's (2009) study on the support made available for children having special educational needs in Sweden. According to the Swedish Educational Act, appropriate support is to be provided to all children identified as having documented difficulties in school. While there is no explicit link between receiving support and a presence of a medical diagnosis, the study shows how within the existing economic constraints of schools, medical diagnosis like autism have taken on a certain position that legitimizes receiving support.

Furthermore, this political use of the label in this study was not only about obtaining certain resources but also to do with access to certain places, for instance schools. An illustration of this is a response of a parent in this study who was asked to withdraw their child from the school. The mother involved

the disability commissioner²⁵ by drawing on her child's disability label to show that school could not ask her child to leave. However this is an isolated example, very few parents with children admitted in private schools would resort to such measures in fear of school back lash. This is despite the fact that the law states that no schools private or public can expel a child on the basis of their disability. However as many private specialists in this study described, schools are aware of this and do not usually directly draw on the disability but find other means of asking the child to leave. There were interesting accounts from parents and specialists of how some private schools admitted children with autism on the condition that they would have to withdraw the child if he was unable to adjust, and some schools who had made parents actually sign binding documents to this effect.

While parents who have children attending private schools cannot always use government policies to ascertain certain rights and resources to be made available to their child because of a disability label, the situation is fast changing in government schools with recent policy developments, such as the SSA (MHRD, 2011). Some of the private specialists in this study did allude to this, by stating that they had recently started encouraging parents of children with certain disabilities to admit their child to a government school instead of those within the private regime. They claimed that within a government school there is the possibility of demanding the provision for support from a special educator among others, which is not guaranteed in a private school. With more resources being stipulated for children with disabilities under the SSA, is likely to result in disability becoming more politicized. The discourse is likely to move towards a desirability of a disability label, and negotiating and renegotiating of services, concessions and examination exemptions, rather than one of stigmatization. Thus the political space highlighted by autism in this study is in many ways a reflection on how the political space around disability is also changing in India.

Social space

As a central focus in this study has been on understanding the interactions between parents and schools, the initial discussion under social space

²⁵ The Chief Commissioner for Persons with Disabilities is mandated to redress the grievances related to deprivation of rights of persons with disabilities and non-implementation of laws and other regulations issued by the State Governments for welfare of persons with disabilities.

concerns the impact of the label autism on the relationship between parents and schools. Evident from the findings in this study is that as soon as parents revealed the diagnosis their relationship with school came under more scrutiny. The characteristics of this changed relationship were discussed in detail in Article III. It elucidates how parents felt obligated to the school for allowing their child with a diagnosis to continue, which resulted in them adopting a non-questioning approach towards the school and teachers. While parents carefully deliberated on what support or changes to request the school for to support their child's continuity in the setting, they were extremely careful in how they approached it with the school so as not to destabilize the set boundaries. In essence parents' relationship with the school was identified as fragile and was constantly being negotiated and renegotiated post disclosure of the diagnosis.

This significantly changed parental relationship with school as a consequence of the autism label becomes more recognizable when it is juxtaposed with parents whose children did not have any such disability label. This is best exemplified in the case of families where siblings were attending the same school as the child with autism. These parents while describing their interactions and experiences with schools for their child with autism often contrasted the case of their 'non-autistic child', where these careful contemplations in interactions with the school were never a concern. Moreover, this also finds support in one case where the parents had not disclosed the diagnosis to the school, wherein their interaction with the teachers took the shape of a parent concerned regarding her child's participation in the classroom rather than that of a parent of child with a medical label.

Nonetheless, it is important to recognize that shared knowledge of the label has the potential to improve relations between the school and the parents. Lauchlan and Boyle (2007) discuss how diagnostic labels in special education provide legitimized explanations for the child's problems in the classroom, which has both positive and negative outcomes. In the Indian setting, where it is common for parents to be blamed for their child's odd behaviours and difficulties (Vaidya, 2008), the autism label could possibly replace teachers' assumptions of parental shortcomings in upbringing and discipline, contributing to a more positive relationship. While this conclusion is hard to draw based on the findings from this study, this does seem plausible when seen in conjunction with other data from teachers' interviews. While talking about the child with autism, teachers often mentioned other children in their classroom

having behavioural difficulties. However, their explanations of the behaviour difficulties for these children were usually rooted in parental lack of involvement or family circumstances, which was never the case when it concerned the child with autism.

Finally, it is important to locate the discussion here in the wider space of the interactions that individual schools in this study chose to maintain with all parents in general and whether this differed for the parents of the child with autism. The interactions between teachers and parents follow the conventional patterns within the school, where some schools gave more importance to it than others. This ranged from schools where any parent had the possibility of contacting the class teacher every week on a particular day and time, to being restricted to official parent-teacher meetings organized each term. However in all the schools, parents could make an appointment with the principal if a wider concern was in question. While these were the available communication channels for parents to contact the schools, it seemed that the teachers could summon the parents at any point. These described patterns of interaction did not differ for parents of children with autism, with the exception of two schools where parents had the possibility of contacting the special educator if they so desired. However in parents' description it was evident that the interaction with the school staff seemed to be dominated by largely a one way flow of information (teachers to parents), thus leaving no space for developing parental-school collaborations.

Moving the discussion forward to another element of the social space reflected in this study: if and in what way did the knowledge of the diagnosis change parents approach to schooling for their child. Findings showed how on a basic level parents' responded to the schooling of their child with autism in a similar fashion as other middle-class families in India. This was also one of the reasons for many of the inconsistencies, dilemmas, and tensions in parents' accounts, which reflected the middle-class thinking but were in contradiction to what parents' perceived their child needed and the hurdles they had or were facing. Despite parents having encountered difficulties with their child's admission into a private school, they did not consider government schools that are obligated to admit every child. This tension is also visible in parents selecting an English medium school, even though many of them saw English as hurdle for their child who was more comfortable in the Bengali language. Similarly, this is evident in their approach to sending their child for private tuitions, although they did not see the child benefitting from it. These

parents' approach to schooling for their child with autism was directed by the middle-class societal space they inhabited, a space with certain inherent beliefs and rules. Nevertheless, while schooling strategies adopted by parents in this study might be similar to other middle-class parents, findings show how having a child with autism made parents more active and strategic in their approach to schooling for their child. Parents were found to be slowly pushing boundaries within the school and bringing about modifications for their child.

Finally, a slowly transforming social space captured in this study shows how private schools that are not obliged to follow government policy were changing in their acknowledgment of responsibility towards children with disabilities in general. While the schools in this study had admitted the child with autism knowingly or unknowingly, they expressed a consciousness of responsibility towards these children, by which they provided varying levels of accommodation. This change is not a result of a new inclusive policy in school or an act of altruism, the two reasons which have commonly been raised as the motive behind private schools admitting and supporting children with disabilities (Jha, 2010; Singal, 2008). On the contrary, these developments have to be understood in the wider space of how disability is entering into the general consciousness of society. Schools and principals in this study are part of a rapidly transforming society where changing perception towards education of children with disabilities are reflected in the media and in the increased policy attention (as will be discussed later in this chapter on pp. 103-104). Thus interestingly findings from this study show how there are private schools now stepping up to take responsibility, even though it is limited to children with autism who are in their school and the types of accommodations made are also questionable.

Educational space

In one way the educational space coincides with the physical place of the classroom, at the forefront being the class teacher. One of the questions addressed by this thesis centered on teachers' perceptions on and practices towards the child with autism, and I reflect here on how these were shaped by the knowledge of the child having the label of autism.

For teachers, the term 'autism' meant no more than it being the name of the child's special need. Consequently their perception of the child and his/her educational needs was not in any way influenced by an understanding

of the autism diagnosis. Dominating teachers' accounts was the notion of child being 'different'. Infused by the understanding of the 'normal' child, they raised personality and behaviour characteristics that varied from the peers. However, significant to note is that these descriptions of the child did not seem to be associated with something negative nor with difficulties arising in the educational setting.

Paradoxically there was an incongruity between teachers' described understanding of the child and their explication of the educational needs. Despite having emphasized the child's intelligence, teachers concerns were largely limited to the child's academic performance. Moreover, having raised the child's need for friends and him/her subject to frequent teasing and bullying, little emphasis was given by teachers to support the child to develop the necessary social and communication skills to negotiate this. Thus teachers' description of the child's educational needs seemed to be motivated by what they saw as important for all children – academics and exam performance, consequently leading to a neglect of the educational needs arising out of the social sphere.

However, looking at the pedagogical impact of the special need label, findings show how in subtle ways it impacted teachers' practices. Teachers were found to be making accommodations and providing support to further the child's participation within the classroom. This for instance was done by them adopting a flexible approach when it came to the norms on acceptable classroom behaviour and/or during assessments and examinations. Moreover the impact of the label is also visible in teachers' reflective decisions regarding what direct supportive input to provide to the child, which behaviour to attend to and which to ignore and where to seat the child among others.

Generally the findings illustrate how teachers pedagogy was determined by wider environmental and cultural factors, extending beyond the knowledge of the special need label. Here it is important to locate teachers' responses in this educational space as embedded and part of other spaces. Firstly teachers' response to the child with autism took place in a space where she was responding to the needs of other children and within the limitations of the existing realities of her classroom. Secondly, her response was embedded in the wider space of teaching in India, the norms surrounding it and the adopted roles and responsibilities. Thirdly, it was shaped by the perceived limitations of the educational system in general with an emphasis on written work, assessments and examinations. Finally, teachers operated within the space of a particular setting

where their practices were determined to a large extent by the frames set by the principals.

Another important stakeholder often associated with the educational space is the special educator. While in this study only a few schools had access to a special educator, some critical concerns surfaced. Permeating special educator accounts was the inadequacy of their educational training which provided them with limited skills to work and support children with special needs within the mainstream. This was also reflected in their restricted and in many cases questionable knowledge of autism. Further, the general understanding of their role in school was largely restricted to compensating for academic shortcomings during classwork, assessments and examinations. Keeping in mind the existing realities of Indian classrooms, special educators can be a critical resource to increase successful participation of children with disabilities. This is now acknowledged by the state, where government schools by law are supposed to provide access to specialist support (MHRD, 2012). However it is important to contemplate what role these special educators are to play and the knowledge base required to do so, an area that need to be explored further.

The educational space for children with autism was not restricted to the school, but extended to the parents as well. In this study the educational space was also exemplified by the constant decisions parents had to make regarding their child's schooling. On one hand it was the choice of school for the child-mainstream, 'inclusive', special, government, private and/or which specific private school. On the other it was also about how to support the child within the school, which parents did in various ways by carefully negotiating conditions within the school, for instance by finding outside support within a school, as in the form of a shadow assistant.

Moreover, schooling was not simply taking place within the classroom. Parents supplemented their child's learning through other means, such as undergoing training on how to teach the child themselves, getting external specialist support and employing private tutors. Parents in this study spent significant amount of time teaching their child. This is not surprising, it is well acknowledged in research studies that in a country where awareness and facilities for autism are limited, parents take on the role of educators (Brezis, et al., 2015; Narayan, et al., 2005). Neither is this centrality of parents in the educational space something specific to autism, findings from Das and Kattumuri's (2011) and Naraian's (2013) study exemplify the central role of parents in

accessing schooling for children with disabilities in general, not only the physical space but also the curriculum.

Contribution of this study

This study has generated academic knowledge on the limited researched area on schooling of children with disabilities in India. It adopted the unique lens of autism to the topic and provides insight on the education of children with autism in mainstream schools. Moreover, it moves beyond perspectival data from stakeholders to incorporate teachers' classroom practices, an area that has been largely excluded in the existing research. While this study was not designed to contribute to practice, the findings raised in the accompanying articles do have clear implications for improving practice. Likewise, without being conducted as a policy study, the study affords significant reflections regarding the existing policies on education of children with disabilities. As the policy and/or practice implications of this study have been raised in relation to the findings in each article respectively, the focus in this section is on the main contribution of the study.

Contribution to the theoretical debates on education and schooling of children with disabilities in India

Education of children with disabilities is no longer restricted to the margins in India (Thomas, 2005). In the last two decades it has gradually become part of the wider educational discourse. Three significant legislations passed in the 1990's set the education of children with disabilities on the educational map. The Rehabilitation Council of India Act (MSJE, 1992, 2000) stated that all children with special needs will be taught by a trained teacher. This was followed by the Person With Disabilities Act (MSJE, 1996), which entitled access to education in an appropriate environment for all children with disabilities up to 18 years of age. Finally, even though the National Trust Act (MSJE, 1999) did not directly touch on education, it drew attention to services and support for a number of neglected disability groups, including autism. The 2000s saw a continued commitment in the policy making on education of children with disabilities, where the Indian government enacted three new policies – Action Plan for Inclusive Education of Children and Youth with Disabilities

(MHRD, 2005), National Policy for Persons with Disabilities (MSJE, 2006) and Inclusive Education of disabled at Secondary Stage (MHRD, 2009a)²⁶.

Simultaneously the last decade has also seen noteworthy developments in the universal education system in India, with the initiation of the Sarva Shiksha Abhiyan programme, the biggest educational movement in the country to provide elementary education for all (MHRD, 2012) and the Right to Education Act (MHRD, 2009b), which stipulates free and compulsory education for all children in the 6-14 age group (MHRD, 2009b). As both these mainstream policy initiatives include children with disabilities within the realm of 'all' children, the education of children with disabilities has now entered the mainstream.

This dynamic nature of the field is further visible in intensification in coverage of education of children with disabilities within the mass media. There are now frequent newspaper columns on the issue, magazines with cover stories on the topic, it is now even being discussed on primetime television debates and talk shows, and recent movies like *Tare Zameen Par* center on disability and schooling. Furthermore, the explosion in the number of websites, blogs, forums and Facebook groups, are also a reflection of this rapidly changing terrain, where education of children with disabilities has gained increased visibility in public discourse. Keeping pace with these changes in policy and the larger society, there has been an increasing academic interest in this area. Academic conferences, books, articles and empirical studies on the topic are also commonplace now than they were a decade ago.

Negotiating access to school for children with disabilities a persisting concern

With this backdrop, some researchers have started questioning the focus in Indian policy and research studies on only *access* to a school which they claim has dominated the discourse on education of children with disabilities. They argue for a shift in focus to the quality of education being provided to these children within the classroom (Lindsay, 2003; Singal, 2010; Singal & Jeffery, 2011). Access to a mainstream school and addressing teacher attitudes towards disability according to Singal and Jeffery (2011) are 'first generation' concerns, where there was a clear focus on the need to increase enrolment. They argue to turn attention towards 'second generation' concerns, which move beyond these surface issues to engage with the curriculum and peda-

²⁶ Details regarding these policies are provided in Article I

gogy being offered to these children within schools and its impact on their education. This is a valid argument, as studies are now showing that there is not only a greater awareness to include children with disabilities into the school system in India, there are also increasing numbers accessing elementary school (NUEPA, 2014; O'Keefe, 2009) but in parallel are the high dropout rates among this group and low educational outcomes, in comparison to others (NCERT, 2012).

However, the findings from this study show that despite these numerous developments and changing discourses surrounding education of children with disabilities, essentially when it comes to the field the question still asked is about negotiating access to a physical space within the school. Even in an urban setting in India, in schools that are well resourced the issue comes down to fighting for a space in the education system. For parents in this study the main concern was how to make sure that their child with autism could actually attend a school that they wanted and the measured decisions parents were making around that.

This continued dilemma of access is supported by findings from a recent study by Naraian (2013) conducted in the urban city of Chennai. Through the lens of educators from an NGO and parents, she shows how gaining access to a school setting for children with disabilities entails a process of negotiation by the NGO educators, where there is a “bargaining during process of admission” (p. 370) with the school. Moreover, the physical accessibility of these children within the setting was entirely borne by parents, who were compelled to hire ‘maids and helpers’ for accessing toilets and negotiating stairs. These findings from Naraian’s research are no different from the self-financed ‘shadow’ employed by one parent in this study or another parent who was asked by the school to find and employ a helper (see Article III). Regardless of the type of disability, autism or mobility impairment, the commonality shared here is to enable some kind of physical access to the school and the classroom, often peripheral to the actual learning that is to take place within the classroom.

Learning of children with disabilities a contested area

While access to and within the school seems to still be a very actual question, recent findings from rural India are showing positive change in teachers’ perceptions and attitudes towards disability and the place of the child in the mainstream (cf. Das & Kattumuri, 2011; Parasuram, 2006; Sharma, et al.,

2009). Singal's (2014) study in Karnataka exemplifies how teachers are more open and willing to accommodate children with disabilities within their classrooms. This is also reflected in the findings in this study where teachers were positively inclined towards the child with autism in their class.

However, the paradox that surfaces in Singal's (2014) study as well as in this one is that despite teachers valuing the participation of the child with disability in the mainstream, they gave little significance to the actual learning that was taking place for the child within their classroom. While teachers in government schools in Karnataka signed up to the government policy discourse of inclusive education and the significance of children with disabilities to be in a mainstream classroom, they saw the main purpose of this as being social inclusion. There was largely a non-engagement with the child's academic learning and access to the curriculum, if any it was limited to minor accommodations like providing longer time on tasks and reducing the curriculum. Moreover, teachers claimed that academic learning of child was to be supported by the experts that are provided through the government SSA policy. Interestingly, while teachers upheld the importance of social inclusion of children with disabilities, they did not do anything to support this actively.

While no similar assertions about social inclusion were made in this study and neither did teachers draw on the need for special educators to teach the child, none of school staff contemplated or asked if the child was actually learning within the classroom. The main support provided by teachers was to enable the child to function in the classroom and to participate in the assessments and examinations that enabled the child to progress through the educational system. It was assumed by teachers and parents alike, that parents would be the ones responsible for the actual learning, which then would be judged by the child's performance in school. Helping children with disabilities access the curriculum is even raised by Naraian (2013), in her study the responsibility seemed to be shouldered mainly by the mothers who spent large part of the day in trying to make the curriculum accessible to their child. Moreover, the external NGO the child was associated with played a central role during public examination by breaking down the curriculum and creating a reduced special syllabus for the child with disabilities, with an aim for the student to succeed in the examination.

Thus learning of children with disabilities within the mainstream continues to be a contested area. Some of the questions this raises are: Who is to be responsible for the child's learning? Why is the child attending the school?

Whose responsibility is it to make the curriculum accessible and for what purpose? Until these questions are not addressed, there will be little gains by addressing the quality of education through the curriculum and pedagogy being offered to children with disabilities.

Shifting focus from inclusive education to 'how' education of children with disabilities can take place

While the aforementioned questions are essential to address for developing this field further, I also want to flag here an issue which impacts education of children with disabilities on a more foundational level. Findings from this study show the entrenchment of the discourse of inclusive education in India and its extensive permeation in government policies and in practice. Alongside this it shows how certain fundamental discrepancies continue to pervade the inclusive education discourse, namely what is inclusive education, who gets included and where. Article I reflected in detail on what the consequences of this on education of children with disabilities is and argued for a critical stance towards inclusive education. Moreover, it emphasized the importance of transferring focus to developing a contextual understanding of 'how' education of children with disabilities can take place in the diverse context of India. I limit myself to just highlighting this contribution here.

Recognising the role of parents as partners in schooling of children with disabilities

Majority of scholarly interest on education of children with disabilities in India has prioritized school staff and policy makers (Das & Kattumuri, 2011; Sharma, 2009; Singal, 2006a, 2008). However there are a few researchers like Jha (2010) and Das and Kattumuri (2011), who have fleetingly included parental accounts in their study on inclusion of children with disabilities into the mainstream. In the aforementioned studies parents are shown to be subject to the authority of schools. On the contrary, what is being exemplified through my research is that even though parents might be disfranchised as being a parent of a child with disability, they are exerting agency when it comes to schooling of their child, as visible in the previous discussion of the medical, political, social and educational spaces that they inhabit. They are making conscious, reflective and nuanced decisions keeping in mind their child's own well-being. The dissonance exemplified through my research is that even though parents are taking responsibility for the education of the child and

making very crucial decisions, they are not being acknowledged or seen as partners in the education system.

The last few years has seen growing literature within the field of general education which shows how parents play a very central role in the decisions regarding their child's schooling across socio-economic groups (Gilbertson, 2014; Srivastava, 2008; Vincent & Menon, 2011). This includes among others their deliberative choice of school, as well as arranging activities outside school for their child, to either support them through their schooling or provide certain advantages. Paradoxically instead of acknowledging this proactive role of parents, it has in research been perceived as something peripheral to the actual discussions around schooling, in line with the school centric discourse around education. Hence it is not surprising that parents continue to remain rather invisible even in the discourse surrounding education of children with disabilities.

Till now parents have been left to the margins and have been largely neglected by educational research. It is time to acknowledge that parents are important partners in this enterprise of educating children with disabilities. Alur (2010) is one who has previously raised this in context of education. She provides a documented example of the success of two projects run by Spastics Society of India²⁷, where parents were involved as partners in the inclusion of their children from a special school to a mainstream school. Only very recently has government policy started recognizing this. While the SSA (MHRD, 2012, p. 49) now includes participation of parents in the discussion of the Individual Education Plan regarding their child with special need, it is a far from a partnership but can be seen as a first step in this direction. While the rhetoric of parents as partners in general seems to exist among principals in private schools in this study, it is far from reflected in their practice.

Concluding thoughts: reflecting back, looking forward

While on one level this study questions the little change that has taken place when it comes to schooling of children with disabilities in India, on the other hand the discussion of 'spaces' shows that things are changing. However, it is essential to acknowledge that this thesis has captured a snapshot in a particu-

²⁷ Today known as Able Disabled All People Together

lar time and space. In the five years since the data for this study was produced the larger disability and educational landscape in India has undergone significant transformation. Not only has the disability movement gained much more prominence, permeation of disability in mass media has intensified. This changing terrain is no better reflected than in the widespread positive response and demand across India to a recent film ‘Margarita with a Straw’, which focuses on sexuality and disability. A topic one would have thought would still be quite controversial in the Indian setting. In parallel, neither has the education system been static. The impact of Right to Education Act (MHRD, 2009b) is yet to be seen. Worth noting also is the changed discourse within the education system which is now driven by a complementary focus on access and quality concerns. This dynamism in the education and disability fields continues and we know little about how this will impact the education of children with disabilities in the future.

Summary in Swedish

Det här är en svensk sammanfattning av avhandlingen *Autism-in-context. An investigation of schooling of children with a diagnosis of autism in urban India*. Avhandlingen i sin helhet består av fyra forskningsartiklar och en kappa.

Utgångspunkter, syfte och forskningsfrågor

Denna avhandling tar sin utgångspunkt i en postkolonialt orienterad kritik relativt funktionshinder i Syd och har som övergripande syfte att öka den kontextuella förståelsen av hur skolning utformas för barn med autismdiagnos i den reguljära skolan²⁸ i Indien. Det var genom personliga erfarenheter av arbete med barn med autism i England, Indien och Sverige som idén att göra en fördjupning runt kontextens roll föddes. Jag fascinerades av hur barn med autism i de tre länderna uppvisade liknande egenskaper, hade samma diagnos men olika kontextuella faktorer tycktes forma hur *autismen* kom att manifesteras, förstås och svaras på av såväl skola som samhället i stort.

Kontext har alltmer blivit en viktig del av diskursen runt inkluderande pedagogik, särskilt när den jämförs mellan länder (Artiles, et al., 2011; Mitchell, 2005). Det är dock bara i aktuella postkoloniala debatter om funktionshinder som kontext har tagits upp som den mest grundläggande faktorn för att förstå fenomenet funktionshinder i Syd²⁹. Grech (2011) betonar att det endast är i en kontext som ett visst funktionshinder ges betydelse. Han menar vidare att det är inom specifika sociokulturella, ekonomiska och politiska miljöer som funktionshinder upplevs, erfars och eventuella möjligheter och begränsningar framträder. Utifrån antagandet att en viss kontext påverkar upplevda verkligheter, erfarenheter och lokala uppfatt-

²⁸ Med *reguljär skola* avses ”den vanliga skolan”, alltså inte specialskola, särskola eller annan skola med särskilda anpassningar.

²⁹ Termerna *Nord* och *Syd* används för att på ett förenklat sätt urskilja två grupper av länder, där skillnaden inte är geografisk, utan representerar en socioekonomisk klyfta. Flera av länderna i Syd har historiskt dominerats av tidigare kolonialmakter i Nord vilket har resulterat i en fortsatt ojämlik relation och beroende. Denna tudelade kategorisering är en förenkling av en existerande heterogenitet, såväl inom länder som mellan länder i samma kategori. Icke desto mindre valde jag att använda Nord-Syd i denna studie eftersom den ger en något mer nyanserad bild än de begränsade stereotypier som inramar t.ex. I-land – U-land, Öst – Väst eller 1:a Världen – 3:e Världen.

ningar, följer studiens huvudfråga: vilka uppfattningar och praktik finns rörande skolning av barn med autism i reguljära indiska skolor?

Den postkoloniala kritiken bidrar med övergripande argument kring varför kontext är viktigt, men den ger ringa stöd i hur ett komplext multidimensionellt begrepp som kontext kan undersökas i denna studie. Givet studiens explorativa anslag, antog jag en pragmatisk hållning för att utveckla ett systematiskt sätt att förstå kontext genom att utnyttja befintlig kunskap och förståelse från Indien. Information som samlades in under förundersökningen kompletterades med litteratur om autism och funktionshinder i Indien för att identifiera fyra dimensioner av kontext som kom att studeras närmare i avhandlingen: skolkontext, social- och familjekontext, kulturell kontext och institutionell kontext.

Utifrån ovanstående dimensioner av kontext kom följande frågor att utforskas närmare:

- På vilka sätt utformar skolan utbildningen för barn med autism?
- Hur förstår och agerar lärarna på de särskilda behoven hos barnet med autism?
- Vilka uppfattningar och erfarenheter har föräldrar om sina barns skolgång?
- Hur uppfattas inkluderande pedagogik inom dessa skolor?

Frågorna har bearbetats i de fyra forskningsartiklarna i avhandlingen.

Bakgrund

Indiens befolkning uppskattas till ca 1,17 miljarder och antalet skolbarn mellan 6-14 år beräknas till 194 miljoner (MHRD, 2008). Detta gör det indiska skolsystemet till världens näst största. Sedan Indiens självständighet 1947 finns allmän skolplikt i grundskolan instiftat i grundlagen. Landet har genomgått en betydande utveckling de senaste 60 åren avseende befolkningens alfabetism, antalet barn som går i skolan samt andelen barn som går ut grundskolan (MHA, 2011; UNICEF, 2011). Trots denna utveckling beräknas runt åtta miljoner barn sakna tillgång till grundläggande utbildning (UNICEF, 2011). Genom åren har landets olika regeringar sjösatt en mängd program och åtgärder i en strävan att nå målet med att alla barn, oavsett kön, kasttillhörighet, socioekonomisk bakgrund och religion ska ha rätt till grundläggande utbildning (Singal & Jeffery, 2011). Flera framsteg har gjorts för olika minoritets-

grupper, men gruppen barn med funktionshinder har under lång tid halkat efter (Miles & Singal, 2010). Utvecklingen på internationell nivå har dock bidragit till att flera policyer riktade mot funktionshinder har lagstadgats även på nationell nivå. Det i sammanhanget mest betydelsefulla dokumentet, *Persons with Disabilities Act, 1995* (MSJE, 1996) skapade en allmän debatt och ökade den mediala uppmärksamheten runt gruppen funktionshindrade som också i någon mån gjorde sitt inträde i den allmänna diskursen. Ytterligare framsteg har gjorts genom olika lokala intresseföreningar som organiserat sig och skapat nationella rörelser (Mehrotra, 2011). Kunskapen om vilken påverkan denna utveckling haft på utbildningssystemet är dock mycket begränsad.

I takt med att gruppen funktionshindrade fick ökad uppmärksamhet riktades även fokus på hur utbildningen ser ut för dem. Utbildning av barn med funktionshinder har under åren adresserats i flera statliga program och satsningar. Det var emellertid först år 2002 som utbildning av barn med funktionshinder kopplades ihop med programmet *Education for All* (skola för alla) på nationell nivå. Av dokumentet framgår att "... alla skolor måste erbjuda inkluderande pedagogik för barn med funktionshinder" (MHRD, 2011, p. 46). Begreppet *inkluderande pedagogik* återfinns som en röd tråd genom alla styrdokument och program inom området (Singal, 2006b). Trots vägledande nationella dokument och det faktum att Indien förbundit sig till att erbjuda grundläggande utbildning för alla, är gruppen funktionshindrade barn i huvudsak fortsatt isolerade från den allmänna utbildningssfären.

Forskning om utbildning för barn med funktionshinder i Indien

Den övervägande delen av litteratur som berör utbildning för barn med funktionshinder i Indien består av verk och artiklar av beskrivande karaktär och är författade utifrån personliga erfarenheter av barn med specifika svårigheter. En annan del behandlar generella fakta om exempelvis särskolor och specialskolor, utbildningsmetoder och inkluderande utbildning (se t.ex. Alur & Bach, 2010; Byrd, 2010). Det finns några få empiriska studier som har undersökt forskningsfältet, men den stora massan av forskning rör statistiska redovisningar på gruppnivå, exempelvis andelen barn med funktionshinder som går i skolan (se t.ex. O'Keefe, 2009). Resultaten från de kvantitativa studierna tenderar att variera, men överensstämmer på den punkten att trots olika ansträngningar från staten är bara en bråkdel av barnen med funktionshinder inskrivna i skolan (Singal, 2009). En annan fåra i forskningsfältet berör lärarens attityder kring barn med funktionshinder samt

inkluderande pedagogik (Bhatnagar & Das, 2013; Parasuram, 2006; Shah, et al., 2013; Sharma, 2009; Sharma, et al., 2009). Sammantaget ger dessa studier en endimensionell och onyanserad bild av det multifaktoriella samspelet i ett klassrum.

Några få studier har med en kvalitativ ansats tagit sig an uppdraget att försöka undersöka och beskriva denna komplexitet. Man har exempelvis studerat skolpersonalens upplevelse av inkluderande pedagogik (Hodkinson & Devarakonda, 2009; Singal, 2004), skolkultur (Sandill & Singh, 2005; Singal, 2008), ledarskapsfrågor och barns egna erfarenheter (Das & Kattumuri, 2011). Det saknas dock till stor del studier som berör vad läraren faktiskt *gör* i klassrummet. Faktum kvarstår att nästan 95 % av den bråkdel skolgående barnen med funktionshinder i Indien inte går i någon form av särskola eller specialskola, utan i vanliga reguljära skolor (O'Keefe, 2009). Kunskapen runt hur skolgången faktiskt ser ut för dessa barn är i dagsläget mycket begränsad och det är detta kunskapsgap som jag försökt adressera i denna studie.

Teoretiska perspektiv

Detta kapitel tar upp de olika perspektiv som påverkat grunden och utformningen av studien. Det inleds med en kartläggning av de bredare debatterna om funktionshinder samt dess inverkan på hur lärandebehov hos barn förstås inom utbildningsområdet.

Det medicinska perspektivet tillskriver problemen till individen som följd av att denne har vissa egenskaper och svårigheter som resulterar i och förklarar skolsvårigheterna (Clark, et al., 1998b). Fokus ligger på att kategorisera, diagnostisera och kompensera genom att vidta särskilda åtgärder. Dess motsats återfinns inom det sociala perspektivet där pedagogiska svårigheter anses uppstå som en följd av sociala processer och där fokus för att eliminera pedagogiska hinder återfinns inom klassrummet, i skolan eller i lagar och styrdokument (Norwich, 2013).

På senare tid har det dock uppmärksamats att det måste finnas en mer holistisk förståelse av funktionshinder än de begränsande dualistiska synsätt som antagits i de medicinska och sociala modellerna (Shakespeare & Watson, 2002). Debatter som denna har bland annat legat som grund till försöken att omdefiniera hur funktionshinder kan förstås, genom att utveckla en biopsyko-social modell av funktionshinder. Världshälsoorganisationen (WHO) arbetade fram begreppen och skapade *Internationell klassifikation av funktionstillstånd, funktionshinder och hälsa* (ICF) (WHO, 2001), som integrerar de

medicinska och sociala perspektiven i en interaktiv och multidimensionell modell. I modellen är kontext integrerad som en betydelsefull del för att förstå funktionshinder vilket är ett signifikant utvecklingssteg. Inflytandet av ICF på utbildningsområdet började också långsamt göra sig synligt, vilket t.ex. Norwich (2013) uppmärksammat.

Det var dock helt nyligen som kontext lyftes fram som det mest centrala i debatter kring funktionshinder. Forskare med ett postkolonialt perspektiv har på senare tid börjat ifrågasätta homogeniseringen av funktionshinderdiskursen i de akademiska kretsarna och i praktiken, där funktionshinder inte bara framstår som taget ur sin historia utan också avkontextualiserats (Ghai, 2002; Grech, 2009; Meekosha, 2011). När jag började min forskning var dessa debatter nya, men under frammarsch. Nu har de blivit centrala och som min forskning har utvecklats över tid har dessa perspektiv starkt påverkat mina tankar och haft en avgörande betydelse för att göra mig medveten om hur funktionshinderdebatter i den Sydliga kontexten konstruerats av synsättet.

Grech (2011) belyser hur Västeuropa och USA har haft något av ensamrätt över frågan om hur funktionshinder ska definieras och förstås. Det handikappvetenskapliga fältets teorier och metoder om funktionshinder har transporterats över jorden, genom den akademiska världen, olika internationella överenskommelser och biståndsorganisationer som okritiskt har antagit den dominerande sociala modellen för funktionshinder. Denna universella funktionshinderdiskurs vilar på antagandet att teoretiska verktyg med rötter i den sociala modellen, anses tillämpliga för att förstå funktionshinder i Syd. Detta har dock ifrågasatts av bland annat Meekosha (2011) som visar att den dominanta sociala modellen som har utvecklats i Nord inte förmår fånga komplexiteten runt funktionshinder, så som den visar sig i historiska, politiska, sociala och ekonomiska kontexter i Syd.

Vidare har det argumenterats att tillämpning av den sociala modellen har reducerat upplevelsen av funktionshinder i Syd till att uteslutande handla om förtryck vilket har lett till ett ensidigt fokus på barriärer och hinder i funktionshinderdiskurser i Syd (Grech, 2011). Den ensidiga debatten handlar uteslutande om vad som *inte* sker eller görs i dessa länder, snarare än att skapa förståelse för faktiska problem och möjligheter för personer med funktionshinder (Singal & Muthukrishna, 2014). Grech (2011) belyser ytterligare en konsekvens av den sociala modellens förtryckarfokus, närmare bestämt att den funktionshindrades makt att själv åstadkomma förändringar i sin situation inte ges något utrymme. Vidare har den allmänna bristen på röster från Syd

inom forskningsfältet för handikappvetenskap varit föremål för kritik. Grech (2009) lägger fram paradoxen att medan majoriteten av människor med funktionshinder lever i Syd (drygt 400 miljoner), har modeller och diskurser av funktionshinder formulerats på grunderna av den funktionshindrade minoriteten i Nord. Detta har Meekosha (2011) kallat för en slags ”vetenskapskolonialism”.

Denna studie tar sin utgångspunkt i den framväxande postkoloniala kritiken av funktionshinder i Syd, i synnerhet deras betoning av kontextuell förståelse. I linje med denna kritik riktas studiens analytiska fokus på att försöka förstå komplexiteten runt skolgången för barn med autism i Indien. Denna komplexitet förstås inte enbart genom västerländska teorier av funktionshinder, utbildning och autism, utan genom en mångsidig förståelse av alla berörda aktörer och deras olika perspektiv. I avhandlingens fokus ligger således inte enbart att identifiera problem, paradoxer och utmaningar som rör skolgången, utan att undersöka dessa och försöka urskilja kontextuella styrkor och hinder.

Ur ett autismsperspektiv

Lorna Wing's (2007) symtomtriad är ett sätt att beskriva vad som anses vara gemensamt för individer med autismsdiagnos och innefattar svårigheter med socialt samspel, bristande utveckling av verbalt och ickeverbalt språk samt repetitiva och stereotypa aktiviteter. Hur dessa svårigheter tar sig i uttryck varierar från individ till individ varför autism vanligen betraktas som en spektrumstörning snarare än ett enskilt syndrom. Trots en god samstämmighet om ovanstående råder det flera oenigheter runt autism som diagnos samt dess etiologi (Grinker, 2008; Nadesan, 2005). Jag konstaterar att diagnosen och dess validitet runt om i världen är ifrågasatt men faktum är att barn med diagnosen autism existerar i Indien och att väldigt lite är känt om deras skolgång.

Det finns en tydlig hierarki runt olika typer av funktionshinder, både bland forskare, i policydokument och den allmänna diskursen i Indien. Ett tydligt fokus har legat på grupper med olika former av fysiska/motoriska funktionsnedsättningar samt hörsel- eller synnedsättningar (Mehrotra, 2011; Singal, et al., 2011). När en specifik grupp på detta sätt får den övervägande uppmärksamheten ökar risken att andra funktionsnedsatta grupper inte får samma fokus. Särskilt svårt att nå fram har det varit för gruppen med osynliga funktionshinder, däribland autism. Trots en kraftig ökning av antalet individer

som diagnostiserats med autism i Indien på senare år (RCI, 2007), har utbildningsfrågorna inte fått någon egentlig uppmärksamhet. Såväl forskning som mediebevakning har visat att många skolor har en ovilja att acceptera elever med autism (Narayan, et al., 2005). I en litteratursökning av publicerade vetenskapliga artiklar inom autism i Indien från 1990 till 2011, återfanns endast två rapporter av 52 som berörde någon aspekt av utbildning eller skola. Kunskapen om hur utbildning och skolgång ter sig för barn med autism är i det närmaste obefintlig.

Metod

Studien använde en etnografisk och tolkande ansats. Dataproduktion utgjordes av semistrukturerade intervjuer, observationer och statliga dokument, för att undersöka de olika dimensionerna av kontext enligt syftet.

Studien genomfördes i Kolkata (f.d. Calcutta), en storstad belägen i den östra delstaten Västbengalen, med en befolkning på ca 14,2 miljon invånare.

Urvalet av informanter utfördes i etapper. I ett första steg identifierades berörda aktörer genom en förundersökning av forskningsfältet och inkluderade barn med autism och deras föräldrar, skolpersonal (rektorer, specialpedagoger, skolpsykologer och lärare) samt privatpraktiserande specialister³⁰. Samtliga av ovanstående aktörer utom barnen med autism är representerade i studien. Anledningen till detta var av etiska skäl, eftersom barnen i många fall inte själva blivit informerade om diagnosen (Basu & Barua, 2009). I ett andra steg valdes informanterna ut genom att de vid tidpunkten för studien hade någon privat eller professionell relation till ett barn med autism i åldern 6-14 år som gick i den reguljära skolan. Åldersgrupperingen valdes med anledning av att barn i denna ålder har skolplikt och således rätt till utbildning. Med tanke på att föräldrarna inte alltid berättade om barnets diagnos för skolan, etablerades endast kontakt med skolor som hade underrättats om densamma.

Den enda metod som bedömdes kunna ge mig tillträda till informanter inom forskningsområdet var snöbollssampling (Mertens, 2010). Eftersom jag tidigare arbetat praktiskt inom fältet hade jag fortfarande kontakt med ett antal privatpraktiserande professionella vilka jag initialt kom att ta kontakt med. Utifrån dessa första möten kunde fler kontakter knytas vilka till slut kom att forma urvalet.

³⁰ Med privatpraktiserande specialister avses privata aktörer, utan koppling till skolan, vilka erbjöd olika pedagogiska, psykologiska och rådgivande tjänster till föräldrar och deras barn.

Det slutliga urvalet av informanter som deltog i studien bestod av 13 rektorer, 11 klassföreståndare, åtta specialpedagoger³¹ och tre skolpsykologer. Sammantaget kom informanterna från 11 privata skolor. Förutom skolpersonal intervjuades 18 föräldrar samt 11 privatpraktiserande specialister. Vidare samlades information in genom 70 timmars observation i klassrum samt informella samtal med lärare i nio av de tidigare nämnda elva skolorna.

Det elva skolorna som ingick i studien var samtliga privata³² och hade engelska som undervisningsspråk. I övrigt var variationerna mellan skolorna stora. De var etablerade någon gång mellan åren 1950 till 2011. Antalet elever sträckte sig från 350 till 2500 och antalet elever i varje klass mellan 20 och 42. Skolavgifterna varierade mellan 750 Rupier till 5500 Rupier per månad. Åtta skolor erbjöd undervisning för både pojkar och flickor, två var flickskolor och en endast för pojkar. Skolorna erbjöd olika läroplaner, både nationella och internationella. Majoriteten av skolorna hade ingen uttalad inkluderingspolicy och antog inte heller avsiktligt barn med funktionshinder. I de flesta fall hade barnen diagnostiserats efter det att de blivit antagna till skolan.

Fyra delarbeten

Nedan följer en kort sammanfattning av de fyra artiklarna, syftande till att lyfta fram de specifika data som de bygger på samt de viktigaste resultaten och slutsatserna.

Artikel I: En kritisk och kontextuell ansats till inkluderande pedagogik: Perspektiv från en indisk kontext.

(A critical and contextual approach to inclusive education: Perspectives from an Indian context)

Efter Salamancadeklarationen, kom inkluderande pedagogik att ingå i statliga policydokument i flera länder i både Nord och Syd. Sedan dess har ett antal böcker och artiklar författats i ämnet, men med mycket begränsad representation från Syd. Fokus för denna artikel är Indien, det näst befolkningsrikaste

³¹ Fem skolor saknade helt specialpedagogkompetens.

³² De senaste två decennierna har privata skolor i Indien haft en snabb tillväxt över hela landet men i synnerhet i städerna (Kingdon, 2007). Privata skolor är självständiga etablissemang med egen ledning och finansieras antingen av privata aktörer och/eller är beroende på höga studieavgifter. Studier har visat att privata skolor i Indien idag inte endast är något för de privilegierade klasserna, utan väljs aktivt av olika socioekonomiska grupper (Nambissan, 2003). Skolavgifterna varierar således kraftigt.

landet i Syd. Den undersöker vilken betydelse inkluderande pedagogik tillskrivs utifrån fyra statliga policydokument samt i praktiken. De dokument som analyserats har antagits under det senaste årtiondet och berör inkluderande pedagogik och/eller barn med funktionshinder. Artikeln bygger också på intervjudata som genomförts i 11 privata skolor med 13 rektorer, åtta specialpedagoger och tre skolpsykologer.

Resultaten visar att under det senaste årtiondet har den inkluderande pedagogikdiskursen förankrats djupare i Indien vilket märks på policynivå men även bland privata skolor som, till skillnad från statliga skolor, inte har skyldighet att följa statliga riktlinjer. Även om termen nu är väl förankrad i Indien, bekräftar resultaten att tvetydigheter kvarstår rörande inkluderande pedagogik i Indien, vilket tidigare uppmärksammats av andra forskare (Hodkinson & Devarakonda, 2009; Julka, 2005; Singal, 2006a, 2008). Variationer i konceptualisering av inkluderande pedagogik var synlig, inte bara mellan skolpersonal och policydokument, utan även mellan olika dokument, till och med de som utvecklats inom samma statliga departement uppvisade påtagligt disparata drag.

Även om det råder enighet om ”det goda” med inkluderande pedagogik och att det endast handlar om barn med funktionshinder, har inkluderande pedagogik tilldelats flera betydelser. En semantisk förvirring syns i analysen av policydokument där orden ”inkludering” och ”inkluderande pedagogik” användes för specifika ändamål. Ordet inkludering används i en bredare betydelse för alla barn och berörde tillgång till utbildningssystemet. Inkluderande pedagogik var däremot en typ av program som erbjöds barn med funktionshinder i syfte att stödja deras närvaro i reguljära skolor. Både inkludering och inkluderande pedagogik användes dock omväxlande av skolpersonal.

Införande av termen inkluderande pedagogik i Indien har också lett till en konceptualisering av ”inkluderande skola”. Genom flera policydokument och i praktiken, betecknas inkluderande skolor som en särskild typ av skola bland andra skolor, exempelvis reguljära skolor och särskolor. Det fanns dock stora variationer i hur den inkluderande skolan beskrevs och tillämpades. Vidare, medan ordet inkluderande pedagogik i statliga policydokument och bland skolorna främst gällde barn med funktionshinder, belystes att det bara handlade om *några* barn, det vill säga de som ansågs ”lämpliga” i att delta i den reguljära skolan.

Mot bakgrund av att termen inkluderande pedagogik har förankrats i den indiska kontexten, tar artikeln upp frågan varför det efter ett decennium inte

bara kvarstår tvetydigheter utan att begreppsförvirringen närmast ökar. Artikeln avslutas med att argumentera för en mer kritisk hållning mot inkluderande pedagogik i Indien och för ett tydligare fokus mot en kontextualiserad förståelse för *hur* utbildning av barn med funktionshinder kan ta form i den indiska kontexten.

Artikel II: "Han är intelligent men annorlunda": Hur berörda aktörer ser på barn med autism i den indiska skolkontexten.

("He is intelligent but different": Stakeholders' perspectives on children on the autism spectrum in an urban Indian school context.)

I denna artikel undersöktes skolpersonals medvetenhet och kunskap om autism samt skolpersonals och andra aktörers uppfattningar om barn med autism i den indiska skolkontexten. Intervjuer genomfördes i sammanlagt 11 skolor med 64 informanter bestående av rektorer, klasslärare, specialpedagoger och skolpsykologer samt föräldrar och privatpraktiserande specialister.

Av resultatet framkommer att kunskapen om autism bland skolpersonalen var varierande men generellt låg. Specialpedagogerna och skolpsykologerna förknippade ofta autism med specifika svårigheter inom vissa områden framför allt språk och kommunikation. Det var dock bara två specialpedagoger som kunde förklara hur dessa specifika svårigheter påverkade barnet i skolan. Vidare framkom det påfallande skillnader och motsägelser i rektorer, specialpedagogers och skolpsykologers kunskap om autism. Gällande lärarna hade endast två av elva hört talas om ordet "autism" innan barnet med diagnosen började i klassen. Lärarna visade heller inget egentligt intresse av att öka kunskapen om autism, det framstod närmast som om termen inte hade någon betydelse för dem.

Resultat från studien visar att lärare, skolpsykologer, specialpedagoger och föräldrar i detalj kunde beskriva egenskaper hos barnet med autism, utan att för den sakens skull koppla ihop dessa med diagnosen eller till möjliga svårigheter som kunde uppstå i skolan. Få lärare benämnde barnet som funktionshindrat. En betydligt vanligare beskrivning var att barnet med autism var "annorlunda" mot övriga klasskamrater, syftandes på beteende och karaktärsdrag. Vidare använde föräldrar, lärare, specialpedagoger och skolpsykologer regelbundet dikotomierna "normal" eller "inte normal" i sina beskrivningar. De upplevde att de "inte normala" det vill säga udda beteendena stod i motsägelse till den "normala" intelligensen som barnet uppvisade. I ett försök

att inordna barnet inom normalitetssfären, betonade såväl skolpersonal som föräldrar ofta barnets intelligens, både generellt och beträffande lärandet i skolan.

En annan aspekt som lyfts fram i resultaten var de utmaningar som barnet med autism stor inför i skolan. Såväl lärare som föräldrar och privatpraktiserande specialister var överens om att dessa utmaningar och svårigheter uppstod på grund av specifika beteenden som barnet med autism visade. Av intresse är att trots att lärarna tidigare betonade barnets intelligens, framstod deras huvudsakliga bekymmer röra barnets studieresultat, i synnerhet akademiska prestationer och skriftliga arbeten. Till skillnad från lärarna, berörde de privatpraktiserande specialisterna svårigheterna som barnet med autism visade inom den sociala sfären, i första hand missförstånd i relation till andra barn samt att de ofta utsattes för mobbning. De betonade betydelsen av att hjälpa barnet med att utveckla sociala färdigheter, men var också tydliga med att den uppgiften inte var ålagd skolan utan föräldrarna. Föräldrarna, å sin sida, lyfte fram både de akademiska och de sociala svårigheterna, men fann sig i att det inte var skolans uppgift att utveckla barnets sociala färdigheter. Såväl lärare, som föräldrar och privatpraktiserande specialister var överens om att skolans uppgift uteslutande handlade om lärande i akademiska ämnen, vilket överensstämmer med den bredare debatten runt utbildningskvaliteten i Indien.

Trots att lärarna hade kunskap och förståelse av att barnet var ”annorlunda” skiljde sig inte deras bemötande av barnet med autism mot bemötandet av de övriga barnen. Lärarna betonade visserligen att barnet med autism hade behov av särskilt stöd på grund av sina svårigheter i skolan, men inte på annat sätt än de skulle gjort för vilket barn som helst vars skolprestationer inte uppnådde förväntad nivå. Detta indikerar att lärarna inte kopplade ihop barnets egenskaper och beteende med svårigheter i skolan. Med lärarnas begränsade kunskap om autism, såg de inte att de egenskaper som förknippas med autism också spelade en viktig roll i barnets studieresultat. Detta problem påpekades ofta under samtalen av såväl föräldrar som privatpraktiserande specialister.

En ökad kunskap om autism bland lärarna hade sannolikt ökat medvetenheten och acceptansen, men resultaten från denna artikel ifrågasätter om barnens behov verkligen skulle uppfyllas i någon högre grad. Artikeln argumenterar snarare för att penetrera vissa antaganden och uppfattningar som återfinns djupt inbäddade i det indiska utbildningssystemet.

Artikel III: "Föräldrar förhandlar förändring": Ett medelklassperspektiv på skolning av barn med autism i Indien.

(Parents negotiating change: A middle-class lens on schooling of children with autism in urban India)

I artikeln studeras och diskuteras föräldrars upplevelser och erfarenheter av barnens skolgång. Fokus låg på föräldrarnas val av skola, hur kommunikationen mellan skola och föräldrar såg ut samt vilka svårigheter som föräldrarna upplevde rörande barnens skolgång. Arton föräldrar intervjuades, samtliga hade ett barn med autism vars huvudsakliga undervisning återfanns i en reguljär privat skola. Barnen var mellan sex och tolv år och bestod av nio pojkar och fyra flickor.

Av resultaten framgår att föräldrarna agerade på ett beslutsamt och aktivt sätt kring den komplexitet som omringade barnens antagning och fortsatta skolgång. De uppvisade en grundlig kännedom och kunskap om möjliga skolalternativ på den privata marknaden. Föräldrarna var taktiska rörande vilka skolor de valde att ansöka till samt vilken information om barnet de presenterade vid ansökningarna, allt för att försäkra sig om att deras barn skulle få tillträde till en specifik skola.

På ett generellt plan var föräldrarna nöjda med barnens skolor. Det framkom dock att skolorna inte hade gjort några egentliga ansträngningar eller anpassningar för barnen. Föräldrarna ställde å sin sida inga krav på skolorna förutom att deras barn fick möjlighet att delta i prov och examinationer som möjliggör uppflyttning till nästa årskurs. Det var således inget krav på att skolan skulle förse eleven med tillräckliga ämneskunskaper för att klara proven, utan denna uppgift ansågs åligga föräldrarna.

Föräldrarna beskrev en värdefull, men också bräcklig relation till skolan. Eftersom skolan hade vetskap om barnets medicinska diagnos, fanns alltid en möjlighet att stänga av eleven. Denna rädsla gjorde att föräldrarna upplevde sig stå i skuld till skolan eftersom deras barn ändå tilläts erhålla undervisning, trots diagnos. Analysen visar dock att föräldrarna var både diplomatiska men samtidigt aktiva i relationen till skolan. De gjorde avvägda bedömningar om när det skulle finnas möjlighet att ställa krav och komma med synpunkter. Detta inkluderade bland annat att delge skolan information om barnets svårigheter eller diagnos, efterfråga särskilt stöd, reducera de akademiska kraven samt väcka frågan om skolan kunde acceptera en elevassistent.

Föräldrarna uppgav flera bekymmer runt sina barns skolgång exempelvis att betygsbedömningarna inte alltid handlade om ämneskunnande, utan snarare om förmågan att presentera materialet såsom det förväntas inom normen dvs. i skriftlig form. När föräldrarna emellertid fick frågan vilka förändringar de skulle vilja göra för sina barn i skolan noterades, intressant nog, att de inte kunde nämna några specifika utvecklingsområden. Möjligen var detta bara ett uttryck för en uppgivenhet om den verklighet de lever i och ett passivt accepterande av de befintliga utbildningssystemen.

Artikeln beskriver hur föräldrarna i denna studie i många avseenden förhöll sig till sina barns skolgång på samma sätt som andra medelklassfamiljer i Indien gör, vilket återspeglas till exempel i val av privata skolor. Trots dessa likheter, belyser artikeln hur föräldrarna till barn med autism gjorde något unikt – de deltog aktivt med att skapa utrymme för sina barn i privata skolor som inte har några lagstadgade skyldigheter att ta emot barn med funktionshinder. I denna process bidrog föräldrarna till att långsamt flytta gränser och skapa ett motstånd mot den rådande uppfattningen bland privata skolor, nämligen att inte anta barn med funktionshinder. Genom att tillmötesgå det rådande *status quo* i skolorna, bidrog emellertid föräldrarna samtidigt till att upprätthålla och normalisera systemet. Artikeln avslutas med att reflektera över denna komplexitet och resonerar om varför dessa driftiga föräldrar inte kunde initiera en större förändring utan istället föreföll relativt anspråkslösa i sina försök att åstadkomma förändringar.

Artikel IV: Lärares respons på barn med funktionshinder i reguljära skolor i Indien: Ett autismsperspektiv.

(Teachers' responses to children with disabilities in mainstream schools in urban India: An autism lens)

I denna artikel utforskas vilka faktorer som påverkade lärarnas praktik och bemötande till barnet med autism. Data från intervjuer, informella samtal med lärare samt 60 timmars klassrumsobservationer ligger till grund för artikeln. Totalt var sju privata skolor inkluderade i studien. Informanterna bestod av sju rektorer, åtta klassföreståndare samt tre specialpedagoger.

Till skillnad från tidigare studier i Indien som berör inkludering av barn med funktionshinder (se t.ex. Das & Kattumuri, 2011; Parasuram, 2006; Singal, 2008) visar resultaten att lärarna generellt var positivt inställda till att utbildning av barn med autism ägde rum inom den reguljära skolan. Utifrån

sin förståelse av barnet använde lärarna olika strategier för att ge stöd och anpassade sin praktik i syfte att främja barnets delaktighet i klassrummet. Lärarna intog en flexibel hållning till barnets olika beteenden i klassrummet men vidtog även små individuella justeringar av läroplanen och vid examinationer. Vidare fattade lärarna noga avvägda och konsekventa beslut rörande allt ifrån var barnet placerades i klassrummet till vilka beteenden som de agerade på och vilka som ignorerades.

I syfte att möjliggöra deltagande i skolan för barnet med autism försökte lärarna ta särskilt ansvar och stötta eleven på olika sätt. Trots dessa olika försök upplevde lärarna en spänning som grundade sig på deras egen uppfattning av förväntningar utifrån tradition och utifrån utbildningssystemet. Förväntningarna handlade om vikten av det handskrivna arbetet, examinationer och betygsbedömningar. Trots en strävan mot att försöka skapa en flexibilitet runt dessa områden var lärarens syn på huvudansvar att ge barnen med autism, på samma sätt som de andra barnen i klassen, nödvändiga färdigheter i att skriva för hand. Syftet med färdigheter i handskrivning var för eleven att få godkänt på prov och examinationer och så småningom möjlighet till att avancera till nästa nivå. Resonemanget blir särskilt intressant eftersom lärarnas upplevda förväntningar inte stod i samklang med någon av de läroplaner som skolorna följde.

Till skillnad från forskningsresultat i Nord (Lindsay, et al., 2013; Robertson, et al., 2003) lyfte inte lärarna i denna studie fram behovet av vidare kunskap om autism för att bättre förstå och stödja barnet. Även om lärarna medgav att barnen hade särskilda behov föreföll det viktigare att göra individuella bedömningar i den faktiska verkligheten i klassrummet. Det dilemma som genomsyrade lärarnas praktik var att hitta en balans mellan deras uppfattningar om barnets behov och den faktiska verkligheten i klassrummet – en verklighet där en klasslärare står ensam ansvarig för i genomsnitt 35 elever, där förväntningarna på läraren var att uppfylla alla de uppgifter och krav som tilldelats dem i relation till behoven hos alla barn i klassen.

Resultaten belyser också hur lärarnas förhållningssätt föreföll vara formade av existerande normer i Indien om hur en lärare ”ska vara”. Dessa normer formade exempelvis lärarens uppfattning om roll och ansvar i klassrummet och styrde inte bara de ansträngningar de gjorde för att utveckla en positiv relation, men också deras bemötande av barnen. Vidare framkom det oskrivna regler lärarna emellan om att inte intervensera i den andres arbete i klassrummet vilket omöjliggjorde alla former av samarbete runt barnet med autism.

Rektorn visade sig ha en avgörande betydelse för vilket förhållningssätt en lärare intog. Rektorn fattade de avgörande besluten rörande matchningen av lärare och barn med funktionshinder samt styrde även över tillgången av specialpedagoger och satte gränser för vilka möjliga anpassningar som kunde genomföras för varje specifikt barn. Viktigast av allt var emellertid vilken betydelse rektorn gav åt deltagande av alla barn i skolans verksamhet och aktiviteter. Detta låg till grund för de ansträngningar och åtaganden som lärarna gjorde, särskilt i förhållande till barnet med autism.

Sammantaget visar resultaten att lärarens praktik inte påverkades i någon betydande grad av faktorer som direkt hade med det individuella barnet att göra, utan snarare av omgivnings- och kulturella faktorer.

Slutdiskussion

Det traditionella sättet att angripa en avhandlings slutdiskussion är att fläta samman studiens olika trådar till en sammanhängande och enhetlig beskrivning. Det handlar om att belysa fynd, ge mening åt resultaten samt skapa och föra fram en berättelse. Det specialpedagogiska forskningsfältet saknar teoretisk förankring (Clark, et al., 1998a) och även de flesta teoretiska perspektiv som tillämpas har sitt ursprung och utveckling i en stark tradition i Nord. Utifrån detta har jag avstått ifrån att försöka utveckla någon liknande *stor berättelse* om skolning av barn med autism i Indien. Meekosha (2011) och Grech (2009) ger en eftertrycklig varning mot detta tillvägagångssätt och menar att man inte ska lockas till att försöka framställa en homogen diskurs från Syd. Det är istället upplevda erfarenheter inom en viss kontext som är centrala.

Genom att lyfta fram den kulturella kontexten, social- och familjekontexten, skolkontexten samt den institutionella kontexten i förgrunden, har en bredare förståelse av den komplexitet som omger skolgången för barn med autism i Indien kunnat synliggöras. I linje med det centrala begreppet *kontext* i denna studie, användes metaforen *rum* (space) i slutdiskussionen, för att presentera och organisera resultaten (Crang & Thrift, 2000; Gulson & Symes, 2007). Detta avsnitt begreppsliggör autism som ett rum för det medicinska, det politiska, det sociala och det pedagogiska.

Under *medicinska rum* diskuteras att även om ett fokus i denna studie var barn med autism, var inte den medicinska diagnosen i sig av något betydande intresse. Jag utgick ifrån barn som blivit diagnostiserade inom autismspektrum och använde istället diagnosen för att utforska vilken form skolgången tar.

Vidare diskuteras den diagnostiska processen i Indien med kopplingar till studien och befintlig forskning, samt i vilken mån processen skiljer sig från länderna i Nord.

I avsnittet om *politiska rum* avhandlas hur etiketten autism används, eller inte används, av berörda parter för att uppnå ett visst syfte. Detta diskuteras sedan vidare i förhållande till politiseringen av funktionshinder i den bredare indiska kontexten.

I *sociala rum* utforskas hur kunskapen om diagnosen påverkar förhållandet mellan föräldrar och skola samt om och på vilket sätt diagnosen förändrar föräldrarnas tillvägagångssätt till deras barns skolgång.

Slutligen, i *pedagogiska rum* analyseras hur lärarnas uppfattningar, bemötande, förhållningssätt och praktik formades av kunskapen om autism. Det pedagogiska rummet som framträder låter sig dock inte begränsas till lärarna, utan sträcker sig även till föräldrarna som inte bara fattade flera avgörande beslut runt sina barns skolgång utan också stod för en betydande del av undervisningen.

Diskussionen om de olika rummen återföljs av en redogörelse för studiens bidrag till kunskapsfältet. Förutom att ha betydelse för policy och praktik, anses studiens främsta bidrag vara till de teoretiska debatterna om skolgång och utbildning för barn med funktionshinder i Indien. Trots utveckling och förändrade diskurser runt utbildning av barn med funktionshinder i Indien, gör den sammantagna reflektionen gällande, att det i allt väsentligt handlar om att förhandla tillträde till en fysisk plats i skolan. Av även större betydelse är frågan om vem som tar ansvaret för lärandet av barn med funktionshinder inom den reguljära skolan i Indien, något som dock fortsätter vara ett omtvistat ämne.

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Sample timetable for grade 4

	08:00	08:30	09:10	09:50	10:30	10:55	11:35	12:15	12:55	13:35
Monday	08:30	English	Math	Science	B R E A K	Social Studies	Story	Hindi/ Bengali	Computer	Physical Training
Tuesday	A S S E M B L Y	Hindi/ Bengali	Math	Social Studies		Environmental Science	English	English	General Knowledge	Craft
Wednesday		Science	Music	Hindi/ Bengali		Math	Social Studies	Computer	English	Environmental Science
Thursday		Hindi/ Bengali	English	Library		Social Studies	Environmental Science	Physical Training	Science	Math
Friday		English	Science	Social Studies	Hindi/ Bengali	Math	Art	General Knowledge	Music	

Details of schools and staff interviewed

	School	Class	Composition	Type	Set up	Who were interviewed	Classroom observation
1	Marina School	Nursery-10	Co-educational	Inclusive	2000s	principal, 4 special educators, class teacher	Yes
2	Vidya Mandir	Nursery-12	Co-educational	Regular	1950s	principal, counsellor, 2 class teachers	Yes in two classrooms
3	Sagar International	Nursery-12	Co-educational	Regular	1990s	principal, special educator, class teacher	Yes
4	Bharati School	Nursery-12	Co-educational	Regular	2000s	principal, head of Junior school, class teacher	Yes
5	Devyani High	Nursery-12	Co-educational	Regular	1970s	principal, special educator	No
6	Hansraj School	Nursery-12	Boys only	Regular	1950s	principal special educator, 2 class teachers	Yes
7	Springdale School	Nursery-12	Co-educational	Inclusive	2000s	principal, 2 special educators, class teacher	Yes
8	St. Joseph High School	Nursery-12	Co-educational	Regular	2000s	principal, counsellor, class teacher	Yes
9	Vista School	Nursery-12	Co-educational	Regular	2000s	principal, head of Junior school	No
10	Shiksha Niketan	Nursery-12	Girls only	Regular	1950s	principal, head of Senior school, class teacher	No
11	Nirmala Public School	Nursery-12	Girls only	Regular	1990s	special educator, counsellor, class teacher	Yes

Details of parents interviewed

	Name	Age	Sex	School type	Grade	School informed of diagnosis
1	Mita	12	Male	Private	6	Yes
2	Gopi	12	Female	Private	7	Yes
3	Nondini	11	Female	Private	6	Yes
4	Parul	10	Male	Private	4	Yes
5	Charu & Girish	10	Female	Private	3	No
6	Renu & Gopal	9	Male	Private	4	Yes
7	Nalini	9	Male	Private	3	Yes
8	Priya	9	Male	Private	4	Yes
9	Uttara & Rahul	9	Male	Private	3	No
10	Usha	8	Male	Private	3	Yes
11	Tara & Kaushik	8	Male	Private	2	Yes
12	Rekha & Mohan	7	Female	Private	3	Yes
13	Kakoli	6	Male	Private	1	Yes

Details of private specialists interviewed

	Name	Profession	Years
1	Mala	Special educator	10-20
2	Priyanka	Special educator	0-10
3	Anushri	Special educator	10-20
4	Shukla	Special educator	10-20
5	Anjali	Special educator	20-30
6	Stuti	Psychologist	10-20
7	Dr. Neerja	Psychologist	10-20
8	Dr.Tultul	Paediatrician	10-20
9	Dr.Kunal	Child psychiatrist	20-30
10	Dr.Shikha	Child psychiatrist	10-20
11	Dr.Sanjay	Child psychiatrist	10-20

Interview guides

Interview guide: Principal

Themes		Sample questions
1.	Background of the person	Tell me a little bit about your background. How long have you been the principal?
2.	School background and characteristics	When and how did the school start? What is the admission procedure?
3.	Inclusive education, special needs and disability	When and how did you start taking in children with difficulties? What does inclusion/inclusive education mean to you? How do you support children with special needs? Are there any courses or training provided to the teachers?
4.	Autism understanding	How many children with a diagnosis of autism are in the school? Had you heard about autism before? What do you know about autism?

Interview guide: Teacher

Themes		Sample questions
1.	Background of the person	Tell me a little bit about your background. How long have you been a teacher?
2.	Children facing difficulties in the class	Tell me about the children facing some difficulty in your class.
3.	Autism understanding	Had you heard about autism before? What?
4.	Student with autism- description, practices	Can you describe the child? Tell me about your experience with him/her.
5.	Collaboration with others	Do you collaborate with other staff in school who also work with the child? How? How much contact do you have with the parents?
6.	Reflections and clarifications from the observation	When you went up to his desk during English, what did you say to him? Why did you ask her to go out?

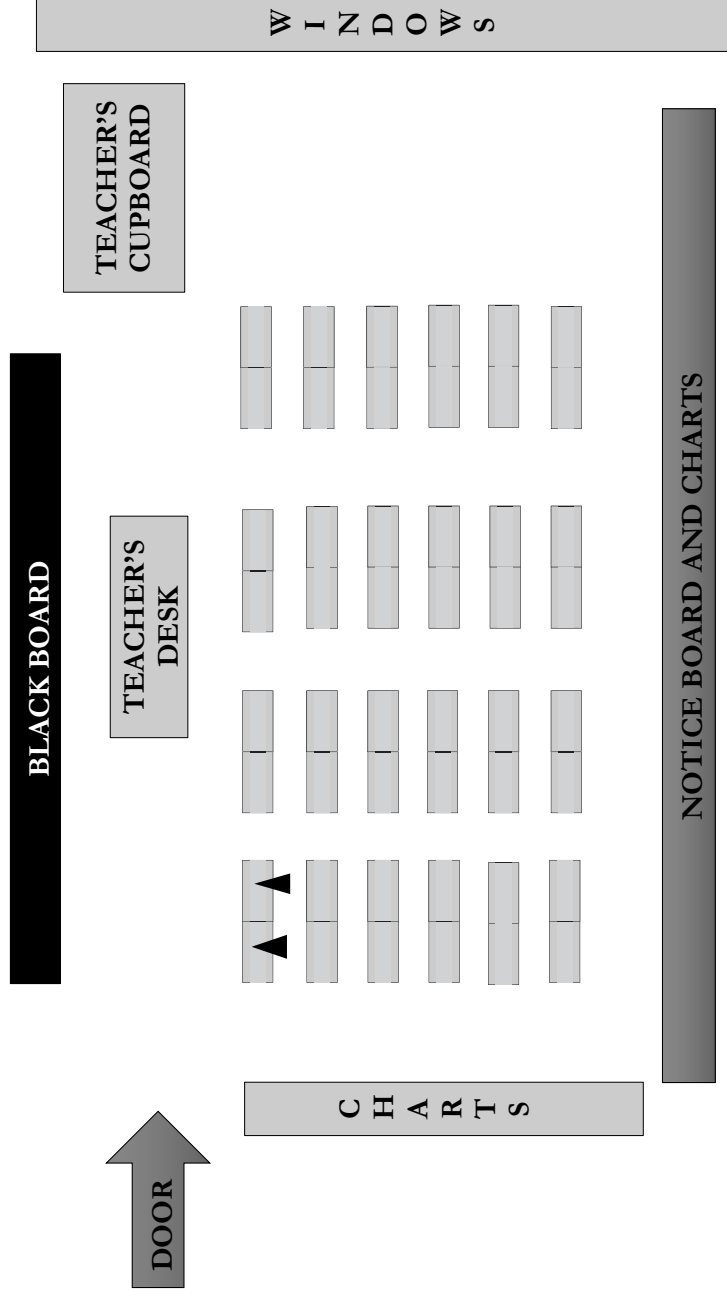
Interview guide: Special educators and counsellor

Themes		Sample questions
1.	Background of person	Tell me a little bit about your background? How long have you been a special educator?
2.	Inclusive education	What does inclusion/inclusive education mean to you?
3.	Children with special needs in the school	Can you tell me about the children with special needs in the school? When and how did the school start taking in children with special needs?
4.	Role in the school	What is your role in the school? Do you provide input to teachers and other children in the school? How?
5.	Autism understanding	What do you know about autism? Can you tell about your experience with children with autism?
6.	Children with autism in the school	How many children with diagnosis autism are in the school? Can you describe the child?

Interview guide: Parents

Themes		Sample question
1.	Basic information about child, school, family	How old is the child? Which school does he attend?
2.	Pre and post diagnosis	Tell me what led to the diagnosis What did you do after that?
3.	Schooling year by year	Can you take me through schooling years of the child year by year?
4.	Support received from school	Does the school know about the diagnosis? What support have you received from the staff at school when you shared the diagnosis and after?
5.	Current school situation	Tell me about how this school year is for your child. Does he have problems with other children in the school? What?
6.	Home situation	How is the situation in the house? With siblings? What does he do when she comes back from school?
7.	Description of the child	Tell me about your child? (likes, dislikes, interests, strengths, weaknesses)
8.	Future concerns and desired changes	What is it that worries you about his future? What changes would you like to make in school for your child?

Plan of a typical classroom



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